

Dementia Resource Guide



ADRC Wolf River Region

1-855-492-ADRC (2372)



**Serving Shawano, Oconto and Menominee Counties
and the Stockbridge-Munsee Community**

Website: www.adrcwolfriver.org

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Additional Web Based Resources:

- Alzheimer's Association - www.alz.org
- American Parkinson's Disease Association (APDA)- www.apdaparkinson.org
- The Association for Frontotemporal Degeneration – www.theaftd.org/
- Lewy Body Dementia Association – www.lbda.org/
- National Institute of Health – Alzheimer's Disease and Related Dementias <https://www.nia.nih.gov/health/alzheimers>
- Teepa Snow – Dementia Expert – www.teepasnow.com
- Wisconsin Alzheimer's Institute – www.wai.wisc.edu
- Wisconsin Department of Health Services Dementia Care System Redesign <https://www.dhs.wisconsin.gov/dementia/index.htm>



Dementia Friendly Community Continued

Music & Memory

An evidence-informed program that provides free personalized music playlists and devices to persons with dementia; as music helps reduce anxiety, calm feelings of agitation, and spark memories.

Purple Angel – Dementia Friendly Business Trainings

Free, on-site, in-person training about welcoming and supporting persons with dementia and caregivers in businesses/organizations.

Respite Care

Respite Care provides caregivers temporary relief from the responsibilities of caring for their loved one and is often referred to as a “gift of time”.

Memory Cafés

Memory Cafés provide a fun, comfortable environment where people with early stage memory loss and their caregivers engage, enjoy, and relax with others on the same journey.

Wandering & Safety

Six out of ten people with Alzheimer's disease will wander at some point. Changes in the brain can cause disorientation even in familiar places. There are a variety of safety products and strategies to address wandering. No device or system can guarantee that a person with dementia will not get lost or they will be found.

Silver Alert www.wisconsincrimealert.gov – Silver Alert is a plan to help local law enforcement in the rescue of missing persons who have cognitive impairment, such as Alzheimer's disease or related dementia. Sign-up to receive alerts via email, cellphone, text, or fax.

Forget-Me-Not Fund

info@forgetmenotfund.org

The Forget Me Not Fund supports the Wolf River Dementia Care and Caregiver Network and the Brown County Dementia Friendly Coalition. Working together, we can keep our fundraising dollars local and help our own communities.

Getting Started...

Whether you or your loved one are living with dementia, this handbook can be used as a starting point for your journey. It's designed to help you better understand and live well with dementia and learn about helpful resources and initiatives in the Wolf River Region.

Staff at the Aging and Disability Resource Center of the Wolf River Region can provide more in-depth information about the resources listed in this handbook, talk with you about your individual situation, and answer your questions.



We are here for you...

Call: 1-855-492-2373

Email: adrc@adrcwolfriver.org

Stop in or make an appointment to see us at one of our locations:

Shawano County

W7327 Anderson Ave

Shawano WI 54166

Monday – Friday 8:00 AM – 4:30 PM

Oconto County

229 Van Buren St

Oconto Falls WI 54154

Monday – Friday 8:00 AM – 4:30 PM

Stockbridge – Munsee Community

Stockbridge – Munsee Elderly Center

N8651 Maplewood St

Bowler WI 54416

Menominee County

Menominee County Human Serv.

W3272 Wolf River Rd.

Keshena WI 54135

Monday & Wednesday

8:30 AM – 11:30 AM or appointment

Wittenberg Satellite Office

Wittenberg Community Center

208 W Vinal St

Wittenberg WI 54499

By appointment only

Lakewood Satellite Office

Northlakes Health Center

15397 Wisconsin 32

Lakewood WI 54138

By appointment only



Dementia Friendly Community

Dementia Capable Emergency Response Training

Free, in-person training for first-responders that provides education on working with people living with dementia in emergency situations.

Dementia Care Specialist

The Dementia Care Specialist (DCS) plays a variety of roles in promoting community awareness, helping build a dementia friendly community, and access to services for people with dementia and their family caregivers. They also consult with law enforcement, community organizations, and others who need information regarding dementia-related issues.

Dementia Live

Provides a free, hands-on experience for anyone seeking to understand what it may be like to live with dementia.

Describe, Investigate, Create, Evaluate (DICE)

DICE is an approach used in assessing and managing behavioral and psychological symptoms of dementia. The DICE Approach walks caregivers through a process to give context to and identify possible causes of behavioral and psychological symptoms of dementia.

In-Home Support

There are a variety of options to bring help and care into the home. Housekeeping, personal care, meal preparation, shopping, medication assistance, and companionship can all be provided.

Long Term Care Funding

Long term care funding is designed to provide a wide range of supportive services in the community for adults with physical and/or developmental disabilities and older adults with long term conditions requiring care. You must be functionally and financially eligible to qualify. The ADRC is the first place to start to explore this option.

Adaptive Equipment

Loan Closets:

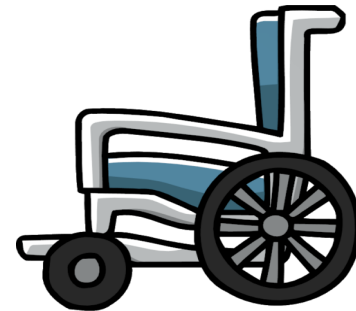
Adaptive equipment loan closets have new or gently used equipment (walkers, crutches, commodes, high rise toilet seats, etc.) for loan. The equipment is available to persons who need it for a short time, would like to try a specific piece of equipment before purchasing, or do not have private insurance or sufficient funds to purchase the equipment.

For more information about loan closets, equipment available, and locations, contact the ADRC at 1-855-492-2372.

Telecommunications Equipment Purchase Program (TEPP):

Telecommunications Equipment Purchase Program (TEPP) TEPP helps people with disabilities with purchasing the specialized equipment they need for distance communications. TEPP is paid for by the Universal Service Fund, which was established by the Public Service Commission of Wisconsin.

608-231-3305



Office For the Deaf and Hard of Hearing:

1 West Wilson Street, PO Box 2659, Madison Wi 53701-2659

1-855-359-5252

The Office for the Deaf and Hard of Hearing (ODHH) provides information and referral services on a variety of topics tailored to the unique needs of **Deaf, Deaf-Blind, or hard of hearing residents.**

What is Dementia?

Dementia is a word used to describe a group of symptoms that affects thinking, memory, reasoning, planning, language, and/or social skills to the point that it affects everyday life. There are many causes of dementia symptoms.

Dementia is not a specific disease. It is an umbrella term for a group of symptoms. Think of it like the word "car". Just as there are many types of cars, there are many types of dementia. Listed below are the most common types of dementia.



Alzheimer's Disease – an illness of the brain that causes a large number of nerve cells to die; which slowly affects one's ability to remember, think clearly and use good judgment.

Vascular Dementia – a sudden medical condition often experienced after a stroke that causes memory loss and confusion due to changes in blood supply to the brain.

Lewy Body Dementia – a disease caused by abnormal protein deposits in the brain called Lewy bodies, which affects one's thinking, movement, behavior, and mood.

Frontotemporal Dementias – disorders that result from damage to nerve cells in the frontal and temporal lobes of the brain, which affects one's thinking and behavior.

- Dementia is not a normal part of aging.
- Alzheimer's disease and dementia are not the same thing. Alzheimer's disease is the most common type of dementia that is not curable.
- Dementia can also occur when people are in their 20s, 30s, 40s and 50s.
- There is more to dementia than memory loss, including behavioral changes.

Signs and Symptoms

Memory loss that disrupts daily life

Challenges in planning or solving problems

Difficulty completing familiar tasks at home, work, or leisure

Confusion with time or place

Trouble understanding visual images & spatial relationships

New problems with words in speaking and writing

Misplacing things and losing the ability to retrace steps

Decreased or poor judgment

Withdrawal from work or social activities

Changes in mood and personality

Research and Clinical Trials

Want to make a difference in the future and lives of people with dementia? Consider becoming a part of a clinical trial or research study to help scientists find ways to prevent and cure dementia. Participants with and without dementia are needed for studies. Talk to the ADRC for more information, or visit these links:

Wisconsin Alzheimer's Institute

608-265-9955

<https://wai.wisc.edu/research/>

Wisconsin Alzheimer's Disease Research Center

608-265-0407

<https://www.adrc.wisc.edu/>

Alzheimer's Association Trial Match

1-800-272-3900

https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials



Power of Attorney (POA)

Having conversations early about health, legal, and financial affairs can help you plan for the future.

What is a Power of Attorney for Health Care?

A POA-HC is a legal document authorizing another person (the “agent”) to make health care decisions for you (the “principal”). The purpose is for you to select someone you trust to make healthcare decisions for you if a time comes that you are no longer able to. It is encouraged that everyone 18 and older should complete a POA-HC document, decide on agents, and discuss their wishes with them.

For a POA-HC to become activated, you (the principal) must be determined “incapacitated” by two doctors, or one doctor and a licensed psychologist. These professionals sign a form stating you are “unable to receive and evaluate information effectively or to communicate decisions to such an extent you lack the capacity to manage your health care decisions.” The certification of incapacity must be attached to the POA-HC document (Section 155.01 (8) of Wisconsin Statutes).

What is a Power of Attorney for Finance?

A POA-F is a legal document that designates another person to manage your finances. This document does not give your agent the power to make medical, long-term care, or other health care decisions for you. The agent’s authority takes effect *immediately* after you execute the document, *unless* you expressly indicate otherwise. You retain the legal right to handle all of your finances as long as you are willing and able, meaning you and/or your agent have authority to make decisions about your finances. POA-F ceases upon your death.

You may request POA-HC and POA-F forms from your attorney, physician, or hospital; pick-up forms at the ADRC; or print forms from the links below

www.dhs.wisconsin.gov/forms/advdirectives/index.htm
<https://gwaar.org/guardianship-resources>

Memory Screening

If you or your loved one are experiencing changes with memory or cognition, it can be scary. Know there are many potential causes for these changes. Some causes (like depression, thyroid disorder, medications, infections, sleep apnea, etc.) can be treated, and the dementia symptoms go away.

Other causes (like Alzheimer’s disease, Lewy Body Dementia, Frontotemporal Dementias, Vascular Dementia, etc.) are not curable and are progressive, meaning there are more symptoms as time goes on.

Early detection of dementia can mean more control of your life and a higher quality of life. While treatments do not exist to cure progressive dementias, treatments focus on managing symptoms and tend to be more effective when taken earlier.

If you notice changes in yourself or a loved one, take action.

A memory screen is a FREE wellness tool that can help identify possible changes in memory and cognition. The screen only takes a few minutes to complete. It is not a diagnostic tool, but it will alert you to any concerns that warrant further evaluation by a doctor; similar to having a stroke, blood pressure, or cancer screen. A memory screen can also be used to set a baseline to monitor any future changes. It is helpful to have a memory screen done annually to detect changes early.

FAQ: How do I get a Memory Screen?

You may walk-in to the ADRC during normal business hours or call 1-855-492-2372 to make an appointment. ADRC staff are trained to provide memory screens, so request one today.

Memory Screens can also be completed by telephone or virtually.



Memory Diagnostic Clinic

The Wisconsin Alzheimer's Institute (WAI) is committed to helping people living with Alzheimer's disease or other dementia, their caregivers, and the health professionals working to support them.

Our **mission** is to promote health equity and improve the quality of life of people living with Alzheimer's disease and other dementias and their families through research, education, clinical care, and community engagement.

Our **purpose** is to increase dementia awareness, provide education on Alzheimer's disease and related disorders, identify and disseminate strategies to reduce dementia risk, convene stakeholders across the state, improve access to quality dementia care services, and to develop and support culturally tailored, effective clinical and community-based models of care.

Memory Diagnostic Clinic staff are specially trained in the diagnosis and treatment of dementia conditions. For a full listing of Wisconsin Alzheimer's Institute (WAI) affiliated dementia diagnostic clinics.

Please visit: <https://wai.wisc.edu/clinic-network/>

CONTACT INFORMATION:

WAI Madison Office:

Phone: 608-263-2862

Email: waimail@mailplus.wisc.edu

WAI WRAP (Wisconsin Registry for Alzheimer's Prevention) Office:

Phone: 608-265-5834

Email: dmwilkinson@wisc.edu

WAI Milwaukee Office:

Phone: 414-219-5083

Email: greenharris@wisc.edu

Helping Children and Teens Understand Dementia

Explaining Alzheimer's disease or related dementias can be difficult.

Explaining to children and teens can be even more difficult. It is important to take time to talk with children and teens in your family so they better understand what is happening, have an opportunity to ask questions, and share their feelings.

Common Reactions

- Confusion about why the person acts differently or doesn't recognize them
- Afraid of the different ways the person may act
- Unsure how to act around the person
- Sad about how the person is changing
- Fear of death or loss of their loved one
- Taking responses personally

Signs of Struggling

- Withdrawing from others
- Losing patience with the person with dementia
- Doing poorly in school
- Spending more time away from the home
- Stop inviting friends to the house

Activities to Do Together

- Read
- Go for a walk
- Put a puzzle together
- Make a favorite recipe
- Eat a picnic lunch
- Watch a favorite movie/show
- Listen to music and sing
- Create a scrapbook of pictures & memories



Changes in Expression & Behavior:

Anyone providing physical, emotional, financial or other types of assistance to a family member or friend with dementia is considered a caregiver.

All behavior is a form of communication, also known as an expression. Often one of the most difficult things about caregiving is understanding and responding to new expressions loved ones develop through the stages of the disease. Expressions like yelling, pacing, wanting to go "home", and swearing can happen as the result of changes in the brain causing more difficulty understanding and responding to others and their environment, along with more difficulty expressing wants, needs, and feelings. Some helpful tips include:

Examine the Expression

- What is it? Is it harmful? Could it be caused by pain, illness, boredom, overstimulation, or something else?

Explore Potential Solutions

- Are the person's needs being met?

Try Different Responses

- Did your response help?

Validate Feelings

- Acknowledge how the person is feeling. People with dementia need to feel understood in a world that is difficult to communicate in.

Notes



Helpful Conversation Tips about Memory Loss

It can be difficult to begin a conversation about one's memory. Below are some suggestions for how to start a conversation about memory concerns.

My memory is not what it use to be:

For example, a person may say “My memory is not what it used to be”. You could respond: “There are many things that can cause memory changes – stress, worry, even vitamin deficiencies. Maybe you could talk with your doctor to find out what is going on.”

Give specific examples of what you have noticed:

For example, you may begin with; “I have noticed that keeping track of appointments has seemed more difficult lately.” Then offer some help (including the importance of seeing a doctor). For example, “How about I help? We can come up with a reminder system and talk with your doctor about it.”

Talk about your own concerns about yourself in order to help the person know that they are not alone:

For example, you could explain; “I have been feeling more like my memory isn't as sharp as it used to be, so I think I will ask my doctor about it the next time I go. Do you ever feel like your memory is changing?”

Talk about the importance of prevention and what can be done to lessen memory changes:

For example, you could say; “I read an article in the local newspaper about memory changes and what can be done about them, so I think I will call my doctor. Let's call and set up an appointment with your doctor too.”

Notes



Local Resources A-Z

The Aging and Disability Resource Center provides a no cost, single point of contact for information and assistance, enhancing self-sufficiency and quality of life. Call the ADRC 855-492-2372 for more information about any of the following resources or to discuss other options that may apply to your specific situation.

Adult Day Service

Anyone experiencing memory loss, confusion, and/or is diagnosed with any type of dementia, including losses associated with stroke and Parkinson's disease, can participate. Activities, personal care, supervision, nutrition, and exercise are available. Adult Day Services provide meaningful activities in a supportive environment. It allows family caregivers to take time to focus on themselves, knowing their loved one is in a safe place.

AFCSP

AFCSP stands for Alzheimer's Family Caregiver Support Program and was created in response to the needs of families caring for someone with Alzheimer's disease and other related dementias by providing some financial assistance to help caregivers access goods and services that will support them in caring for their loved one at home.

Alzheimer's Association

The Alzheimer's Association works on a global, national, and local level to enhance care and support for all those affected by Alzheimer's disease and related dementias, as well as their caregivers. Online and in-person Family & Community Education classes available on a variety of topics.

24/7 Helpline: 1-800-272-3900

Website: www.alz.org

Green Bay Office: 920-469-2110

When a Person Denies Memory Changes

Support the person's perception while still encouraging they obtain an evaluation. For example, you could respond; "You are probably right and it may be no worse than anyone else's, but it would make me feel better if we have it checked out."

As a last resort, if trying to discuss with the person doesn't seem to work, you may need to set up the appointment yourself and inform the person that the appointment is set. You may also want to share symptoms with your loved one's doctor so they can follow-up.

For more information on preparing for a doctor appointment, contact the ADRC at 1-855-492-2372 today.



After the Diagnosis

After a diagnosis, it is important to learn how you or your loved one can live well with dementia.

There are many supports available in the community for people living with dementia. The ADRC can help you figure out which supports work best for your individual situation, values, and preferences. To talk with someone at the ADRC, call 1-855-492-2372.

Some options of resource that may be available include:

- Support Groups
- Educational Events
- Social Activities
- And More!

The links to the booklets below share some ways for how to get started:

<http://www.actonalz.org/pdf/Living-Well.pdf>

<http://www.actonalz.org/pdf/Taking-Action.pdf>



Caregiving & Dementia Resources

Every day brings a new challenge. Make your life as a caregiver easier by learning new strategies to make caregiving less stressful and more enjoyable. The ADRC has a selection of books for caregivers to loan or consider taking some of these online courses, which can be done at a time most convenient for you:

Dementia-Capable Wisconsin: A Guide for Family Caregivers

<https://www.dhs.wisconsin.gov/dementia/families.htm>

The course is free and you may exit and return to the course as often as you need.

Alzheimer's Association Caregiving Trainings

<https://alz.org/help-support/resources/care-training-resources>

Free online courses for caregivers. Some courses are offered in person. Contact the Alzheimer's Association at 1-800-272-3900 for more information.

UW-Oshkosh Dementia Training for Family & Friends

https://wss.ccdet.uwosh.edu/stc/dhsdementia/cst_Generalist_Family_coursesdescrip.htm

Coupon to take this course at no cost may be available. Contact the ADRC at 1-855-492-2372 for more information.

Wisconsin's Family Caregiver Support Programs:

<https://www.wisconsin caregiver.org>

VA Caregiver Support:

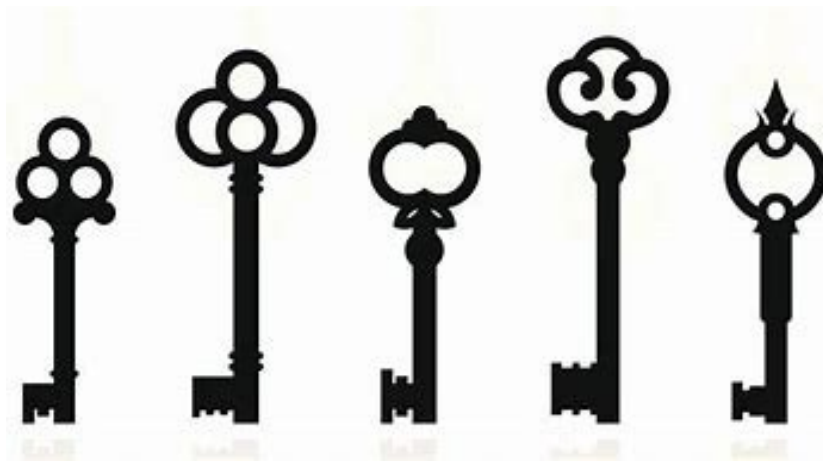
<https://www.caregiver.va.gov>

1-855-260-3274

The Key to Good Communication

Listed are some helpful practice tips to have a positive care-giving relationship:

- Speak slow and clear, with a gentle and relaxed voice.
- Always approach from the front and identify yourself.
- Keep good eye contact and be mindful of your body language.
- Break instructions down into small and simple steps, one at a time.
- Ask yes/no questions instead of open-ended questions.
- Be specific.
- Avoid correcting, quizzing, or teaching & do not argue with a person with dementia.
- Do not take responses personally.



Living Well With Dementia

Partner with your doctor to learn more and ask questions about what type of dementia you have, medication options

Gather information, learn all you can about the disease and what to expect now and in the future

Do not be afraid to talk to others about how you feel (counselor, family, friends, pastor, social worker, ADRC staff, support groups, etc.)

Work with your family and/or an attorney to review or create a Power of Attorney for Healthcare and Finance

Learn about options and resources available in the community

Work with your family to create a care plan for your future needs based on your values and preferences

Exercise regularly and eat healthy

Join a support group and/or attend a Memory Cafe (see page 16)

Remain socially connected to friends, family, clubs, church, etc.

Learn how you can continue to live safely in your home

Read about safe driving tips (visit www.alz.org/driving)

Activities are an important part of staying socially, physically, and cognitively active and will help your mood and improve your quality of life