

Dementia Handbook



ADRC of Marinette County
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Getting Started

Whether you or your loved one are living with dementia, this handbook serves 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 the initiatives of Marinette County.

Staff at the Aging & Disability Resource Center (ADRC) of Marinette County can provide more in-depth information for resources listed in this handbook, talk with you about your individual situation, and answer questions you have.

TABLE OF CONTENTS

PAGE

3	What is Dementia?
5	Memory Screens
6	Memory Diagnostic Clinics
7	Talking with Someone with Memory Concerns
8	After the Diagnosis
9	Power of Attorney
10	Research/Clinical Trials
11	Caregiving
12	Helping Kids & Teens Understand
13	Local Resources
17	Additional Resources



What is Dementia?

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

Important Things to Remember

- 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. The following page will illustrate this concept and discuss some of the more common types of dementia.
- 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 is not just an "old person's disease." Even people in their 20's and 30's have developed some forms of dementia.
- There is more to dementia than just memory loss.

Signs & Symptoms

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, work, or at 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 judgement
- Withdrawal from work or social activities
- Changes in mood and personality

Source: www.alz.org



DEMENTIA

Alzheimer's Disease

- Younger Onset
- Normal Onset

Symptoms

- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months - 1 year

Other Dementias

- Metabolic diseases
- Vitamin deficiency
- Depression

Vascular Dementias

- Younger Onset
- Normal Onset

Symptoms

- Sudden changes
- Picture varies by person
- Can have bounce back & bad days
- Judgement and behavior "not the same"
- Spotty losses
- Emotional & energy shifts

- Infections
- Metabolic disease

Lewy Body Dementia

Symptoms

- Movement problems - Falls
- Visual hallucinations
- Fine motor problems - hands & swallowing
- Episodes of rigidity & syncope
- Nightmares
- Fluctuations in ability
- Drug responses can be extreme & strange

- Malnutrition/Dehydration
- Medication/Drug interaction

Frontotemporal Lobe Dementias

- Many types

Symptoms

- Frontal - impulse and behavior control loss
 - Says unexpected, rude, mean, odd things to others
 - Dis-inhibited - food, drink, sex, emotions, actions
- Temporal - language loss
 - Can't speak or get words out
 - Can't understand what is said, nonsense words

If you or a loved one experience 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 Dementia, 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, the thing is *to do something*.

MEMORY SCREENS

A memory screen is a **FREE** wellness tool that can help identify possible changes in memory and cognition. It is not a diagnostic tool but 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. A memory screen only takes a few minutes. It is helpful to have a memory screen done annually to check any changes early.

How Can You Get a Memory Screen from the ADRC?

Walk-in during normal business hours:
Monday-Friday,
8:30 am - 4:30 pm or
call (715) 732-3850 to make an appointment

ADRC staff are trained to provide memory screens, so request one today!

MEMORY DIAGNOSTIC CLINIC

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/>

TALKING TO SOMEONE WITH MEMORY CONCERNS



When a person mentions a memory concern

For example, s/he may say, "My memory is not what it used to be." You could respond, "There are many things that can cause memory changes such as stress, worry, even vitamin deficiencies. Maybe you could talk with your doctor to find out what is going on."



What if the person doesn't mention any concerns?

Give a specific example of what you have noticed. For example, "I have noticed that keeping track of your appointments has seemed more difficult lately." Then offer more 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 concern about yourself in order to help the person know that he or she is not alone. For example, "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, "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."



What if the person seems to deny memory changes?

Support the person's perception while still encouraging he or she obtain an evaluation. For example, "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 s/he can follow-up.

Contact the ADRC for a checklist to help prepare for a doctors appointment

AFTER A DIAGNOSIS

LIVING 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 (715) 732-3850.

The booklets listed below share more ways to live well with dementia:

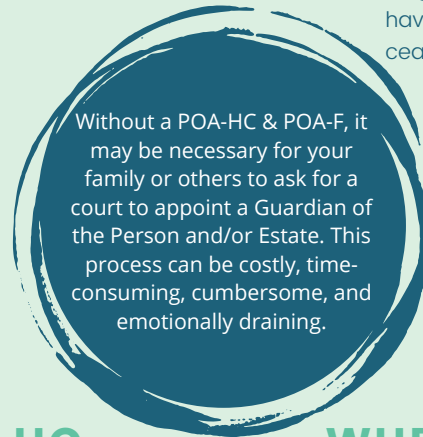
www.actonalz.org/pdf/Living-Well.pdf

www.actonalz.org/pdf/Taking-Action.pdf

- 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 your community
- Work with your family to create a care plan for your future needs based on your values and preferences
- Exercise regularly & eat healthy
- Join a support group and/or attend a Memory Cafe
- 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. If you're looking for activity ideas contact the ADRC we will be happy to discuss options with you!

WHAT IS A POWER OF ATTORNEY FOR HEALTHCARE (POA-HC)?

A POA-HC is a legal document authorizing another person (the "agent") to make healthcare 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 no longer can. Everyone 18 and older should complete a POA-HC document, decide on agents, and discuss their wishes with them.



Without a POA-HC & POA-F, it may be necessary for your family or others to ask for a court to appoint a Guardian of the Person and/or Estate. This process can be costly, time-consuming, cumbersome, and emotionally draining.

HOW DOES A POA-HC BECOME EFFECTIVE OR ACTIVATED?

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 healthcare 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 (POA-F)?

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 healthcare 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.

WHERE CAN I GET THESE FORMS?

A Wisconsin POA-HC form is available:

- At the ADRC
- Online at (www.dhs.wisconsin.gov/forms/advdirectives/index.htm)
- Hospitals and Clinics
- Pastoral Care departments at local hospitals are available to help complete a POA-HC
- A POA-HC can also be completed by an Elder Law Attorney

Information and POA-F forms are available:

- At the ADRC
- Online at the WI Guardianship Support Center (www.gwar.org/wi-guardianship-support-center.html)
- A POA-F can also be completed by an Elder Law Attorney and is encouraged due to the complexity involved

RESEARCH / CLINICAL TRIALS & ADAPTIVE EQUIPMENT

RESEARCH & CLINICAL TRIALS



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

- **Wisconsin Alzheimer's Institute:** (608) 263-2862
www.wai.wisc.edu/research/research.html
- **Wisconsin Alzheimer's Disease Research Center:** (608) 263-2582
www.adrc.wisc.edu
- **Trial Match:** (800) 272-3900
www.alz.org/research/clinical_trials_find_clinical_trials_trialmatch.asp

ADAPTIVE EQUIPMENT

Assistive equipment loan closets have new or gently used equipment for loan at no cost or for a small contribution. The equipment is available to persons who need it for a short time, would like to try a specific piece of equipment before purchasing, have Medicare, are underinsured/uninsured or lack funds to purchase the equipment.



For more information on loan closets, equipment available, and locations, contact the ADRC at (715) 732-3850.

CAREGIVING & DEMENTIA

CHANGES IN EXPRESSION & BEHAVIOR

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 expressing wants, needs, and feelings. Some helpful hints 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 his/her 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.

THE KEY TO GOOD COMMUNICATION

Practice some of these tips to have a positive caregiving 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

CAREGIVING WITH DEMENTIA TRAINING

Everyday brings a new challenge. Make your life as a caregiver easier by learning new strategies to make caregiving less stressful and more enjoyable. Consider taking some of these online courses, which can be done at a time most convenient for you:

- [UW-Oshkosh Dementia Training for Family & Friends](https://wss.ccdet.uwosh.edu/stc/dhsdementia/psciis.dll?linkid=692532&mainmenu=DHSDEMENTIA&top_frames=1) |
https://wss.ccdet.uwosh.edu/stc/dhsdementia/psciis.dll?linkid=692532&mainmenu=DHSDEMENTIA&top_frames=1
 - Coupon to take this course at no cost may be available. Contact the ADRC at (715) 732-3850 for availability.
- [Alzheimer's Association Caregiving Trainings](https://alz.org/care/alzheimers-dementia-care-training-certification.asp) – <https://alz.org/care/alzheimers-dementia-care-training-certification.asp>
 - Some courses are offered in person. Contact the Alzheimer's Association at (800) 272-3900 for more information.

HELPING KIDS & TEENS UNDERSTAND DEMENTIA

Helping Children & Teens Cope

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 him or her
- 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 for Children & Teens, and Loved Ones with Dementia

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

Many more options exist. Contact the ADRC for more information to help support your family, including children and teens.

LOCAL RESOURCES

The Aging & 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 (715) 732-3850 for more information about any of the following resources or to discuss other options that may apply to your specific situation.

AFSCP

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. Contact Marinette County Elderly Services for more information at (715) 854-7453.

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 are available on a variety of topics.

- 24/7 Helpline: (800) 272-3900
- Website: www.alz.org
- Green Bay Office: (920) 469-2110

POWERFUL TOOLS FOR CAREGIVERS

A six-week workshop that teaches family caregivers strategies to take better care of yourself while caring for a loved one. Classes are offered in a variety of settings throughout the year.

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.

LOCAL RESOURCES, CONT.

ADRC LENDING LIBRARY

The ADRC has books available on a variety of topics (i.e.: caregiving, dementia, nutrition, and other helpful topics). Stop by the ADRC to browse the lending library.

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 & RESPITE

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. Are you a caregiver who needs some time to go out for your own activities or simply have some time for yourself? Respite care can also be provided in the home so someone is able to see to your loved one's needs while you see to your own.

LONG TERM CARE FUNDING

Long term care funding is designed to provide for a wide variety of support 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.

LOCAL RESOURCES, CONT.

PURPLE ANGEL – DEMENTIA FRIENDLY BUSINESS TRAINING

The Purple Angel is a universal symbol of hope, comfort, and inclusion without stigma, raising awareness about dementia. Originating in the United Kingdom, Norman McNamara, a man living with dementia, created the symbol when he began training businesses to better understand dementia and provide dementia-friendly customer service. When businesses are dementia friendly, people can continue to do everyday tasks, remaining connected to the community.

Purple Angel Dementia Friendly Business training is available in Marinette County through the **Dementia Friendly Community Coalition**. Employees of businesses and public institutions (restaurants, grocery stores, banks, shops, libraries, etc.) are trained to offer hospitality and support to people experiencing memory loss, confusion, or other symptoms associated with dementia. Suggestions on creating a dementia friendly physical environment are also provided.

Dementia Friendly businesses are identified by the Purple Angel decal displayed in their windows. People with dementia and their caregivers can be confident they will be welcomed warmly and receive extra assistance, as needed.



MEMORY CAFES

Find laughter, friendship, and engaging activities* at Memory Cafes! They offer a fun, relaxing and comfortable environment for people with mild memory loss, dementia, or mild cognitive impairment. Spouses, family members, friends, or caregivers are welcome! Come and enjoy the company of others on the same journey. Register with Maria (715) 330-5025.

*All programmed activities are designed to be comforting, yet stimulating, for persons with dementia.

The Cottages

2006 Lake Park Dr.

Marinette, WI 54143

Date: 3rd Wednesday

Time: 1:00 - 2:30 PM



LOCAL RESOURCES, CONT.

CAREGIVER SUPPORT GROUPS

Support groups for caregivers of loved ones with Alzheimer's Disease and other dementias meet throughout Marinette County.

Care & Share (Peshtigo)
350 N. Stephenson Ave.
Peshtigo, WI 54157
Date: Wednesdays
Time: 9:00 -11:00 AM

Contact June (715) 938-3589

Care & Share (Menominee)
2901 13th St.
Menominee, MI 49858
Date: Wednesdays
Time: 4:30 - 6:00 PM

Caregiver Connection (Crivitz)
516 N. US Hwy 141
Crivitz, WI 54114
Date: 4th Monday
Time: 10:30 AM

Contact Angie (715) 854-7453

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 she/he will be found. For more information on wandering, visit the Alzheimer's Association website (www.alz.org) or Helpline (800) 272-2900 or call the ADRC at (715) 732-3850.

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. Silvers Alerts are broadcasted to the public on roadways, lottery terminals, email and text messages. Sign-up to receive alerts via email, cell phone, text, or fax.

Project Lifesaver - A program available throughout Marinette County that combines "tried and true" radio technology with rescue teams from the local community including law enforcement to build an effective life-saving system to quickly locate individuals with cognitive disorders who are prone to the life threatening behavior of wandering. It is proven and effective method of "bringing loved ones home." Call the ADRC at (715) 732-3850 for more information on this program.

ADDITIONAL RESOURCES

WEBSITES

- Alzheimer's Association - www.alz.org
- Caregiving with Purpose -
<https://caregivingwithpurpose.com/category/alzheimers>
- National Institute of Health - Alzheimer's Disease - www.alzheimers.gov
- Teepa Snow - Dementia Expert - www.teepasnow.com
- Wisconsin Alzheimer's Institute - www.wai.wisc.edu
- The Association for Frontotemporal Degeneration - www.theaftd.org
- Lewy Body Dementia Association - www.lbda.org
- Wisconsin Department of Health Services Dementia Care System Redesign -
www.dhs.wisconsin.gov/dementia/index.htm



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