



Dementia Handbook

A Guide for Your Journey



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Caregiving and 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 understanding and responding to others and the environment, along with 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_frame=1
 - Coupon to take this course at no cost may be available. Contact the ADRC at (920) 448-4300 for availability.
- **Alzheimer’s Association Caregiving Trainings** | <http://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 and 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 question, 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 ADRC for more information to help support your family, including children and teens.

Source: www.alz.org

Local Resources

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 at home.

Powerful Tools for Caregiving

Six-week workshop that teaches family caregivers strategies to take better care of yourself while caring for a loved one. Classes 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 service 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.

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: (800) 272-3900 *Website:* www.alz.org
Green Bay Office: (920) 469-2110

**The ADRC is your
"INFORMATION STATION"**

*Call (920) 448-4300 for
more information about any of
these resources or to discuss
other options that may apply
to your specific situation.*

Local Resources, cont.

Share the Care

Share the Care can offer relief from the stress of caring for a loved one by bringing together a caring community of people to provide assistance to someone they know. The ADRC is an official Share the Care station with information about how you can develop a Share the Care team for yourself or a loved one.

ADRC Lending Library

The ADRC has books and videos available on a variety of topics (i.e.: caregiving, dementia, nutrition, and other helpful topics). Stop by the ADRC's 300 S. Adams Street, Green Bay location to browse the lending library.

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. Transportation may also be available. Adult Day Service provides 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.

Mind Movers

Mind Movers is a program specifically designed for those experiencing early signs of memory loss or dementia. Mind Movers classes provide cognitive exercises, spark creativity, and offer physical activity in a supportive atmosphere to promote brain health.

In-Home Support & Respite Care

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 range 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 the first place to start to explore this option.

Additional Resources

Wandering and 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](http://www.alz.org) (www.alz.org) or Helpline 1(800) 272-3900 or call the ADRC at (920) 448-4300.

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. Silver Alerts are broadcast to the public on roadways, lottery terminals, email, and text messages. Sign-up to receive alerts via email, cellphone, text, or fax.

Websites

- ◇ Alzheimer's Association — www.alz.org
- ◇ Caregiving with Purpose — <http://caregivingwithpurpose.com/category/alzheimers>
- ◇ National Institute of Health—Alzheimer's Disease — <http://nihseniorhealth.gov/alzheimersdisease.toc.html>
- ◇ 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



Dementia Friendly Community Coalition

The Brown County Dementia Friendly Community Coalition brings together professionals, businesses, residents with dementia, and family caregivers to take steps to make our community a better place to live for people with dementia.

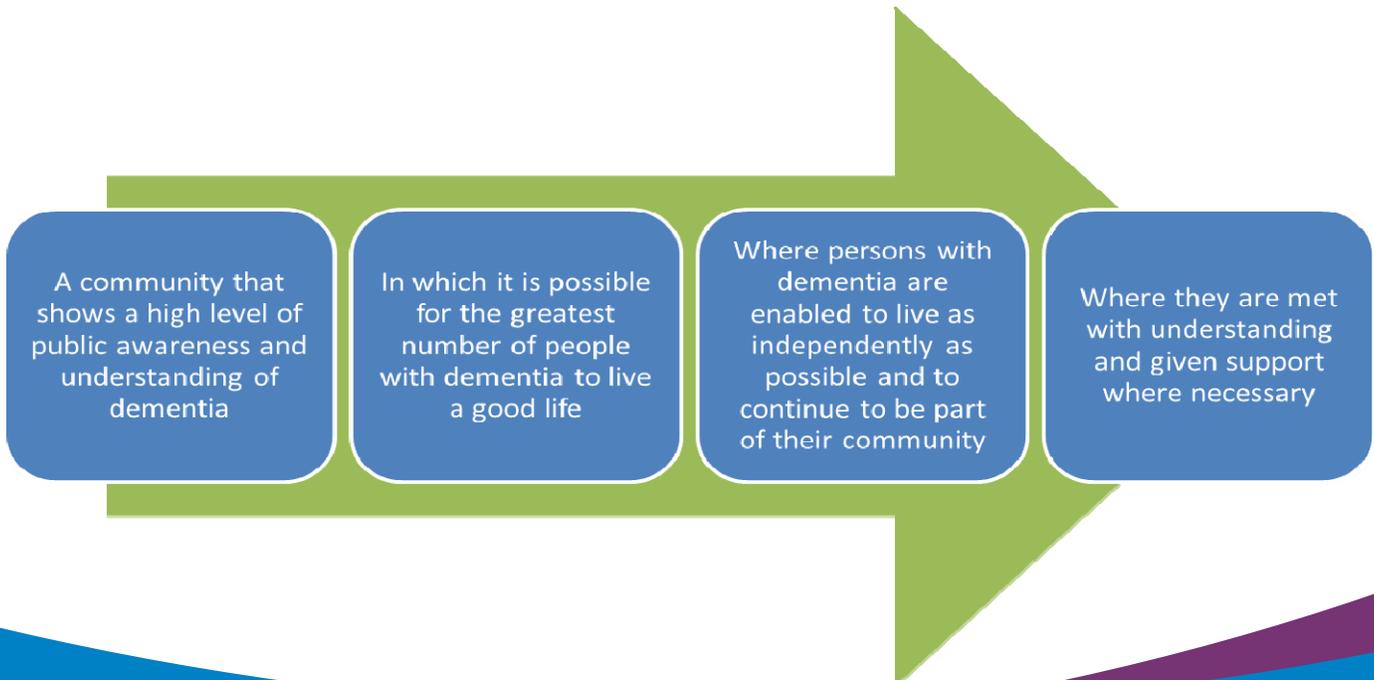
Vision *Transforming Aging, Transforming Community, Venerating All*

Mission *Develop cooperative partnerships which raise awareness, educate, and engage all to create a dementia friendly community that enhances quality of life for everyone.*

Goal *To make quality of life measurably better in our Brown County community by easing the fear, stigma, and isolation associated with dementia, and by increasing access to the resources so people can live well with dementia.*

Learn More Call ADRC (920-448-4300) for more information about any of the Brown County Dementia Friendly Coalition Initiatives explained in this booklet:

- Purple Angel Initiative, page 16
- Memory Café, page 16
- Down Syndrome and Alzheimer's, page 17





Purple Angel Initiative

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 Brown County through the Dementia Friendly Community Coalition Purple Angel subcommittee. 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 Café

Get updates! Like us on Facebook.

 [BrownCountyMemoryCafe](https://www.facebook.com/BrownCountyMemoryCafe)

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 Renee Erickson (920-412-9960).**

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

Monthly Locations

ADRC

300 S. Adams St., Green Bay

Date: 3rd Wednesday

Time: 10:30am-12:30pm

Denmark Senior Center

141 Highridge Ave., Denmark

Date: 3rd Thursday

Time: 1:00—3:30 pm

Green Bay Botanical Garden

2600 Larsen Rd., Green Bay

Date: 2nd Tuesday

Time: 1:00—3:00 pm

Kress Family Library

333 N. Broadway, De Pere

Date: 4th Thursday

Time: 1:00—3:00 pm

St. Paul's Episcopal Church

2809 Flintville Rd., Suamico

Date: 1st Wednesday

Time: 1:00—3:00 pm



Down Syndrome and Alzheimer's Disease

The Dementia Friendly Community Coalition's Down syndrome & Alzheimer's subcommittee is committed to learning about community needs surrounding Down syndrome & Alzheimer's, helping the community through awareness, education, and support.

Adults with Down syndrome are at a greater risk of developing Alzheimer's disease, and at a younger age, than those who do not have Down syndrome. Short-term memory loss is often not the first symptom of Alzheimer's disease in people with Down syndrome.

*Early symptoms can include:

- Reduced interest in being sociable, conversing, or expressing thoughts
- Decreased enthusiasm for usual activities
- Decline in ability to pay attention
- Sadness, fearfulness, or anxiety
- Irritability, uncooperativeness, or aggression
- Restlessness or sleep disturbances
- Seizures that begin in adulthood
- Changes in coordination and walking
- Increased noisiness or excitability

*Source: www.alz.org

**Screening Tool: NTG-EDSD

This dementia screening tool is designed specifically for individuals with intellectual disabilities (referred to as NTG-EDSD or National Task Group-Early Detection Screen for Dementia). This tool keeps track of the functioning of a person with Down syndrome. Starting as early as possible in adulthood, caregivers can document "normal" everyday behaviors. When the screen is completed annually, changes in the individual's level of functioning can be identified that may be signs of dementia.

**Source: www.wibpdd.org

Support Group: Down syndrome & Alzheimer's Caregivers

Families of people living with Down syndrome & Alzheimer's disease are welcome to come together in a comfortable environment to work through challenges and learn from each other. Please call ADRC with questions at (920) 448-4300.
Date: 2nd Tuesday every month
Time: Varies. Call ADRC at (920) 4438-4300 for current meeting times.
Location: ADRC of Brown County (300 S. Adams St., Green Bay)

Additional Resources

- National Down Syndrome Society: (800) 221-4602 | NDSS.org
- National Association for Down Syndrome: (630) 325-9112 | NADS.org
- Down's Syndrome Scotland | www.dsscotland.org.uk
- National Task Group on Intellectual Disabilities & Dementia Practices www.aadmd.org/ntg



“Building a community that values, empowers and supports seniors, adults with disabilities , and their caregivers.”

(920) 448-4300

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