



dementia's impact

There is so much pain to endure when watching a loved one suffer with Alzheimer's disease. There is the pain of perpetual grief. There is the raw wound of continual loss. There is the struggle to preserve dignity and the desire to respect the present and cling to the past. However, in the midst of the heartache there is a small glimmer of light that exists to remind us of the things that Alzheimer's can't take away... the warmth of a touch, the importance of smiles and laughter, and the knowledge of what it truly means to experience unconditional love and acceptance. —Unknown

Dementia in Wisconsin

Even as the number of people who will face dementia in their lives increases, the number of people who are the primary source of caregiving is decreasing. In Wisconsin in 2015, it is predicted that there will be 6.6 people between the ages of 45 and 64 for every one person over the age of 80.

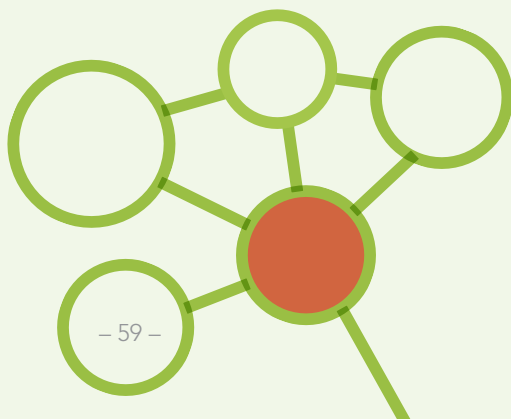
The average age of caregivers is 49, and in 2040, the projected number of people at that age will decrease to 2.7 for every one person over the age of 80. Because the chances of developing a dementia are one in three at age 85, it is anticipated that there will be an increased demand for support for people with dementia and a shortage of family caregivers.⁶

The establishment of dementia-friendly initiatives in Wisconsin can provide assistance to meet the anticipated needs of individuals with dementia, their caregivers and communities.

Impact on Caregivers

In 2013, Americans provided 17.7 billion hours of unpaid care to people with Alzheimer's disease and other dementias.⁷ Providing care for an individual with dementia can place demands on a caregiver's own health and emotional well-being. Although caregivers report some positive feelings, including family togetherness and the satisfaction of helping others, they also report high levels of stress related to providing care, including a strain on finances and family relationships.

Caregivers can also experience depression, sleep disturbances and an impact on their physical health. As a result of the chronic stress, physiological changes can occur, including high levels of stress hormones, reduced immune function, and slow wound healing, resulting in an increased use of health care by caregivers.⁷



Additional information on the impact on caregivers can be found at the following websites:

- www.alz.org/downloads/Facts_Figures_2014.pdf
(2014 Alzheimer's Disease Facts and Figures)
- www.alz.org/care (Alzheimer's Association)

Note: The term caregiver has been used in the tool kit to refer to anyone who provides care to an individual with dementia. Increasingly, people in the dementia field are referring to *care partners* as individuals who provide various forms of unpaid care to individuals with dementia whether at home or in long-term care. The term caregiver is being used for individuals who are paid for providing care to the individual with dementia.

The stress of dementia caregiving is influenced by...dementia severity, how challenging the caregivers perceive certain aspects of care to be, available social support and caregiver personality.

— Act on Alzheimer's Minnesota



Personalizing Communication

Person-centered care is based on recognizing personhood as the foundation for caring for those with dementia and includes recommended approaches for communication, interaction and engagement. This form of personal communication focuses on the strengths, abilities and life stories of the person with dementia rather than on limitations. The opportunities for meeting the individual's psychological needs for attachment, comfort, identity, occupation and inclusion are enhanced through this approach and can result in an improvement of the responses from the person with dementia. A personalized approach concentrates on the positives by knowing what is meaningful to the person with dementia and honors his/her current reality.

Stop thinking, 'This person is confused; she has dementia,' and start thinking, 'I'm confused; I don't know what she is trying to tell me.' -Unknown

Below is an example of personalized communication that can assist community members when interacting with an individual with dementia.

"When a person with dementia is troubled, try to think of magic words to make them feel better if you were in their shoes."

Examples:

- I will be here all day if you need anything.
- Don't worry. I'll take care of it.
- You are pretty important around here.
- If you need anything, just let me know.
- I do silly things like that, too.
- Between the two of us, we will be OK.
- You are a pretty special person.
- Wow, you are so smart!
- Thank you, I couldn't have done it without you.
- That's a good idea. I'll have to try that!
- You always look out for me.

Source: "Creating Moments of Joy" by Jolene Brackey





Living a Meaningful and Productive Life with Dementia

There are many individuals with dementia leading meaningful and productive lives. Many tools and resources exist that can significantly improve quality of life as an individual goes through the stages of dementia. Dementia need not be viewed as an individual tragedy; instead, it can be better understood as an experience of personal change that occurs within a community.

Proactively managing changes and symptoms can significantly improve the quality of life through all stages of the disease for individuals with dementia and their caregivers. Education and caregiver support that works to identify and acknowledge what the individual with dementia can still do, while enhancing the ability of the family to provide care, helps to maintain the individual's independence as much as possible. Through lifestyle changes and support systems, the family can help the individual with dementia manage his/her symptoms, maintain functional abilities, understand changes, prepare as needed to make adjustments, and allow involvement in planning for the individual's future.⁴

Individuals with dementia and their caregivers describe what is needed to live well in **The Seven Quality of Life Outcomes** (below). The following list provides guidance for consideration when implementing dementia-friendly community initiatives. Communities should acknowledge the potential for all to live as independently as possible and continue to access activities safely.

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs.
3. I have support that helps me live my life.
4. I have the knowledge and know-how to get what I need.
5. I live in an enabling and supportive environment where I feel valued and understood.
6. I have a sense of belonging and of being a valued part of family, community and civic life.
7. I know there is research going on which delivers a better life for me now and hope for the future.

(The National Dementia Declaration for England, Dementia Action Alliance 2010)

DEMENTIA-FRIENDLY COMMUNITY EFFORTS IN OZAUKEE COUNTY



The groundwork for becoming a dementia-friendly Ozaukee County began at an Aging Consortium meeting in late 2013. The community was invited to hear about the initiative and gauge local interest. Attendees included senior programs and services professionals, government representatives, caregivers and advocates.

A workgroup was formed to assess where to start and who to involve. The county I-Team addressed the topic at every meeting. The Aging and Disability Resource Center (ADRC), the Alzheimer's Association of Southeastern Wisconsin and the Caregiver Coalition of Ozaukee County collaborated on a memory café that started in April 2014 at the Flipside Café in Grafton. The memory café became so popular that an additional café location began in January 2015 at the Riveredge Nature Center.

Those involved in the countywide effort addressed underutilization of the Wanderers Registry, a free service to county residents coordinated by the ADRC and law enforcement to maintain a database for those who may be at risk if they live alone. The application and information was revised and is now called the Safety Registry and includes all information necessary to issue a Silver Alert. Additional information was added for law enforcement to make their interactions more positive.

Dementia-friendly business training is beginning. Two businesses had staff participate in awareness training and evaluated their environments and procedures to be supportive of individuals with dementia. Other business trainings are scheduled or in the planning process.

Dementia awareness is growing, and collaborative efforts continue in Ozaukee County.

For information, contact the Ozaukee County Dementia Care Specialist at kglaser@co.ozaukee.wi.us.