

Caregiver Chronicles

Spring 2017



AREA AGENCY ON AGING OF DANE COUNTY
2865 N SHERMAN AVE, MADISON, WI 53704
608-261-9930
[HTTPS://AAA.DCDHS.COM/](https://aaa.dcdhs.com/)



When you deal with a person who's experiencing dementia, you can see where they're struggling with knowledge. You can see what they forget completely, what they forget but they know what they once knew. You can tell how they're trying to remember.

—Walter Mosley

Caring for those with Alzheimer's and Dementia

Happy Spring!

Along with the turning of the season this year comes a Spring issue of *Caregiver Chronicles* that combines the latter half of April and the month of May. The Area Agency on Aging was down a fulltime position for the past six months, but we are fully-staffed again and the newsletter will return to its monthly format in June.

The focus of this issue is on resources for those who are caring for individuals with Alzheimer's and Dementia. In a Dutch Study published on April 5, 2017, in the *International Journal of Geriatric Psychiatry*, investigators found, "Suicidal thoughts are present in dementia caregivers and can persist across the care trajectory. . . . More research is needed to enable the identification of high-risk caregivers and provide an evidence base for the development of preventive strategies and interventions." (See page 9 for a link to the study.)

In Dane County, we are fortunate to have outstanding resources and programs for caregivers of individuals with Alzheimer's and Dementia. Joy Schmidt, Dementia Care Specialist for the Aging and Disability Resource Center of Dane County, describes her work on behalf of caregivers, Dementia Friendly Communities, and other specially-tailored programs in her article beginning on page 2.

Caregivers of all ages and backgrounds with loved ones who have Alzheimer's or Dementia will also find excellent resources like the "Time for Us Camp" for youth ages 10—18, and a new telephone support group and Google Hangout. Check out details on page 7.

At the end of April, the VA Caregiver Program is sponsoring a Caregiver Day Off with free classes for caregivers of veterans or vets who are caregivers. Details are on page 8. And now that the good weather is coming and it is easier to get out and about, we'll share information on events that caregivers can attend and the whole family can enjoy, along with low-cost or free events that offer social engagement opportunities for senior adults. "Senior Day at the Duck Pond" offers the opportunity for older adults to get outdoors and be social while enjoying America's pastime. Details on page 9.

As always, please let us know how we can support you on your caregiving journey.

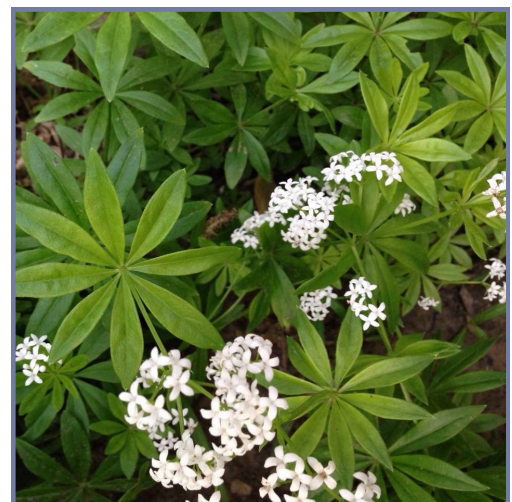


A handwritten signature in black ink that reads "Jane De Broux".

Jane De Broux
Caregiver Program Coordinator
Dane County Area Agency on Aging



Phone: 608-261-5679
Email: debroux.jane@countyofdane.com



Caregiver for Someone with Alzheimer's or Dementia? How Dementia Care Specialists Can Help

Dementia Care Specialists Work Statewide

The work of the Dementia Care Specialists (DCS's) vary around the state depending on the need of each county. They create support groups, memory cafes, and dementia friendly communities. They provide education about dementia and brain health. Some are developing transportation options and most are working with police and first responders to address crisis response for people living with dementia. There are currently 19 DCS's covering 26 counties in Wisconsin. In many areas, the DCS is the only dementia-related resource available.


DCS's have supported countless people living with dementia and their caregivers through programs such as Memory Care Connections and LEEPS (Language Enriched Exercise Plus Socialization). Much of what a Dementia Care Specialist does is work one-on-one with people who have dementia: to help them get a diagnosis; to understand their diagnosis once they get one; and to help support them so they can remain in their own home as long as possible. This often takes bringing families together to better understand how the disease affects an individual so they understand how to communicate with them and help them to cope with memory changes and loss, and loss of independence.

Dementia Care Specialist work in Dane County

Dementia Friendly Communities

In Dane County, we've brought together Alzheimer's agencies, communities, businesses, government agencies, faith-based organizations, hospitals, first responders, and citizens to create dementia friendly communities.


[Click here to read the annual report.](#)



*I'm so happy to live in a community that is dementia friendly.
Knowing that people care and understand makes me feel really good.
When my wife needed to go to the hospital by ambulance, the EMTs really
knew how to help her so she wasn't afraid.*

—Dane County Caregiver

Education



The DCS provides education about dementia and brain health by coordinating available resources and collaborating with a variety of agencies including MSCR (Madison School and Community Recreation), libraries, senior centers, community centers, and other groups. The DCS coordinated a Brain Health Series that brought in experts to present on topics including exercise, sleep, research, nutrition, stress reduction mindfulness, music, and more. The DCS also provided a number of community education programs and collaborated with Alzheimer's agencies to promote their programs.

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LEEPS


In Dane County we have matched 22 people with this service, oftentimes utilizing students from UW-Madison. It has been beneficial to bring students into the work with people who have dementia, and it has provided a respite for some caregivers as well. It's a vital way to help people living with Alzheimer's and dementia stay active and engaged. Participants have been able to remain in their home longer because of this program. One gentleman was homeless due to his dementia and a LEEPS volunteer was able to exercise with him, provide socialization, and connect him to music by using an MP3 player. Participants have loved having this service and we always have a waiting list. With more volunteers, we could make it available to more people.

Memory Care Connections (MCC)

This evidence-based program has been shown to help participants remain in the home 18 months longer on average. Each day an individual remains in the community—instead of expensive institutional care—saves taxpayers \$161/day or \$58,925/year. If a DCS helps two people remain home for 18 months through Memory Care Connections, the program has paid for itself. To date, we have served 46 people in this program. MCC helps to educate the family about the disease and the best ways to communicate with and care for their loved one with dementia. It helps bring people together to establish a care plan and to work towards a common goal. It helps increase communication and acceptance of the disease process. It helps families cope and brings support to the primary caregiver.

Individual and Family Consultations

A DCS spends much of their time working individually with people who are concerned about their memory loss and with their families through specific challenges that arise. For example, a sister-in-law (SIL) of a person with dementia (PWD) heard about the program through her workplace and contacted the DCS. The individual with dementia was still driving and refused to go to the doctor. The SIL didn't know what to do. She wanted to talk to the spouse of this individual but didn't know how to broach the topic. She got advice from the DCS about how to talk to him. While the spouse was relieved the issue was out in the open, he couldn't convince his wife to get



As I'm sure you're aware, the topics of Dementia and Alzheimer's can certainly generate anxiety and even fear for many of us. The information and education you provided went a long way to dispel myths and to better equip us with knowledge about the disease and more importantly, to provide resources and information to help! I especially appreciate your presenting the topic with sensitivity, insight, humor, and hope!

—Participant in Educational Program

Your expertise and guidance during the last months were monumental. I would not have wanted to go through this without you.

—Family member, individual counseling



help. The DCS was able to meet with the spouse, SIL, and PWD, and by building their trust, was able to get permission to talk to the physician. The physician then contacted the PWD to ask her to come in for an evaluation. The medical evaluation determined there was vascular dementia in the frontal lobe and Alzheimer's disease. Through education and support, the DCS helped to make the next steps smoother for the family. The DCS was able to help them avoid a crisis situation which also saves the county money.

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Dementia Capable ADRC

Another role for the DCS is to work with the ADRC to help them become more dementia capable. The DCS provides trainings and guidance on performing memory screens and understanding the dementia diagnoses and neurocognitive disorder language from the DSMV (Diagnostic and Statistical Manual of Mental Disorders). The Dane County DCS coordinated a group of Information and Assistance Specialists to function as the Dementia Team leads who help to disseminate information across the organization. They have provided 113 memory screens and outreach to over 4,000 people in the past year.

Looking Forward

Dementia Care Specialists work hard to collaborate and not to duplicate services. In the early stages, people are not always willing to go to an agency that has “Alzheimer’s” in the title, and even senior centers can intimidate some. Dementia Care Specialists open a door that may be easier for people to enter so we can then get them to the resources they need. Currently, there are almost 7,000 people living with dementia in Dane County with projected numbers to be over 12,000 by 2030. Keeping up with the demand is already a challenge. We need to support our citizens living with this disease, their caregivers, and communities.

—Joy Schmidt, Dane County Dementia Care Specialist, ADRC

Working with the Dane County Dementia Care Specialist

You can contact Dementia Care Specialist, Joy Schmidt, through the Aging and Disability Resource Center (ADRC) of Dane County. Call 608-240-7400 and your call will be routed. It’s the most efficient way to get help and referrals. There are times when an Information and Assistance Specialist can get you started with what you need, and then refer you on to the Dementia Care Specialist for more specific support.

Keep Dementia Care Specialists Available in Wisconsin

Alzheimer’s and dementia is the 6th leading cause of death in Wisconsin. Over 1,800 of our fellow citizens statewide succumbed to the illness in 2014. As our state’s population ages, the number will continue to grow. The number of Wisconsinites expected to suffer from some form of dementia is expected to reach more than 240,000 by 2040. Unfortunately, current funding for Dementia Care Specialists in Wisconsin expires in 2017, and continued funding was not included in the governor’s proposed 2018—2019 state budget.

In a letter to individual Dane County Legislators in the State Senate & Assembly and Joint Committee on Finance Members, the Area Agency on Aging of Dane County Board of Directors Chair, Bill Clausius, wrote:

More than 7,000 people with dementia live in Dane county. In 2016, the Dane County Dementia Care Specialist had 445 contacts and made 681 referrals for services to such agencies as the Alzheimer’s Association and Alzheimer and Dementia Alliance of Wisconsin. . . . In addition, Dane’s DCS had 277 outreach events attended by 4,800 participants. The DCS worked with 16 communities and helped 232 businesses and organization become Dementia Friendly certified . . . Dementia Care Specialist funding must be included in the 2018-2019 state budget to enable continued services to affected senior adults.

If you would like to support continuation of the Dementia Care Specialist Program, contact your state legislators. You can learn more on the [Save Wisconsin’s ADRCs Facebook page](#).



Telephone Caregiver Support Group

Presented by:
Alzheimer's Association
Greater Wisconsin

Last Tuesday of every month 10:00am - 11:00

To Register: 1.800.272.3900
Persons registered will receive the monthly call in phone number a few days prior to the scheduled telephone support group meeting.

Facilitator: Sharlene Bellefeuille, Outreach Specialist

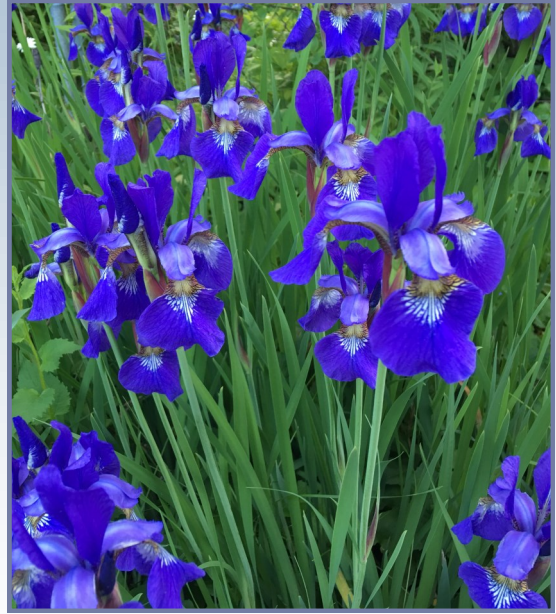
Questions? 1.800.272.3900

Build a support system with people who understand.

Alzheimer's Association® telephone support groups provide emotional, educational and social support for caregivers through regularly scheduled meetings. Held via telephone to accommodate individuals who are unable to travel to a meeting site, these groups help participants develop coping methods and encourage them to maintain their personal, physical and emotional health.

800.272.3900 | alz.org®

Spring 2017



Google Hangout Support Group for Caregivers of Any Age

Third Wednesday of the Month

7:00 PM

Contact: Bonnie Nutt

bnutt@alz.org or call 608-203-850



Time for Us Camp June 11th - June 16th, 2017

TIME FOR US is a great camp opportunity for youth ages 10 to 18 who have a loved one with neurological challenges of the Alzheimer's, Parkinson's, ALS, Post Traumatic Stress Disorder or similar Memory/cognitive challenges. Our nature-based *Keepers of Memories* activities help campers & families find paths toward: understanding changes, coping skills, nutrition, and connections between cognitive health and the health of our environment. Past campers expressed, "It was great!" and "I can once again play with my Dad"

This year TIME FOR US will be moving to BETHEL HORIZONS camp located in Dodgeville outside of Madison, adjoining Governor Dodge State Park. Bethel Horizons camp not only complements our nature-based concept, but also adds the structure and support of a fun five day camp experience.

For 2017... We are continuing to encourage adults to participate in a side by side camp experience at the same time. The adult version is meant for care partners, relatives, persons who work with seniors and people wanting to communicate better and understand more about cognitive health.

Junior Leader opportunities for youth ages 17+

9th Year!

Watch this YOUTUBE to learn more: <https://youtu.be/xRd5OzLrHA>

Sunday, June 11 to Friday, June 16, 2017

Located within Bethel Horizons Camp - Sharing their camp opportunities

forMemory, Inc
Building Hope in Early Onset Cognitive Change, Alzheimer's & Related Disease
Christine Van Ryzin, Camp Coordinator
821 W. Browning St. Appleton WI 54914
920-734-9638
cbvanryzin@gmail.com
www.forMemory.org


Alzheimer's & Dementia Alliance
Formerly the Alzheimer's Association South Central Wisconsin Chapter
517 N. Segoe Rd. Suite 301
Madison, WI 53705
608-232-3400
www.alzwisconsin.org

BETHEL HORIZONS
CAMP
4601 C. Rd ZZ
Dodgeville, WI 53533
608-257-3577
www.bethelhorizons.org

Caregiver Chronicles

Madison VA Hospital **Caregiver Day Off: Fri. April 28, 2017**
Room B-2055

**Free classes for
Caregivers of Veterans
Or
Vets who are Caregivers**

9am-12pm
Taking Care of Yourself

1pm-4pm
Managing Stress



CLASSES and refreshments provided.

Please come to this event. Take one or both classes. RSVP is necessary to save your space in class.

To RSVP call **608-256-1901**, ext. **11451**. Leave a message on the phone of Amanda Sherry; to include:

- YOUR NAME and your Veteran's name
- PHONE NUMBER you can be called back at
- **LUNCH is included If you attend BOTH CLASSES**

For more information, please contact:
Margaret Flood, LCSW
Caregiver Support Program at the
William S. Middleton Memorial Veterans Hospital
2500 Overlook Terrace, Madison, WI



**Connecting People with the
Assistance They Need**

Open 7:45—4:30 pm Monday through Friday

Call (608) 240-7400

Visit the ADRC office, 2865 N. Sherman Ave., Madison

Website: www.daneadrc.org

Email: ADRC@countyofdane.com

The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over two years

This recent article (April 5, 2017) was published in the *International Journal of Geriatric Psychiatry* in response to knowledge that family caregivers of people with dementia often report high levels of stress and depression. "In the coming decades, the number of people with dementia is expected to increase substantially (WHO 212), and alongside this, the demand for family care will also increase. The majority of care for people with dementia is provided at home by family members (Bonsanquet et.al., 1997; Johnson et.al., 2000), which can be very challenging and burdensome."



SENIOR DAY AT THE DUCK POND

TUESDAY, JUNE 20

GAME TIME: 12:05 PM
GATES OPEN: 10:30 AM




+

+

= \$14

Reserved Terrace Seat
Official Mallards Hat
Hot Dog, Soda, and Chips



Reserved picnic tables for your group under tailgate tents for lunch service

★
Lunch served in our tailgate area between 10:30am - 12:30pm

★
Meet the players pre-game

★
Opportunities for autographs post-game

TO PURCHASE TICKETS, CONTACT DYLAN SIMKIN AT 608-246-4277 OR DYLAN@MALLARDSBASEBALL.COM.
 The Duck Pond at Warner Park ★ 2920 N. Sherman Ave ★ Madison, WI 53704 ★ ph. 608-246-4277 ★ MallardsBaseball.com

Caring for the Caregiver Program

AREA AGENCY ON AGING OF DANE COUNTY

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Madison, Wisconsin 53704



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Email: debroux.jane@countyofdane.com

Save paper and reduce postage costs

Please let us know if:

- You are willing to receive the newsletter via email
- You are no longer interested in receiving the newsletter

Contact:

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