

# Caregiver Chronicles

April 2016



AREA AGENCY ON AGING OF DANE COUNTY  
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608-261-9930  
[HTTPS://AAA.DCDHS.COM/](https://aaa.dcdhs.com/)



Photo by Jane De Broux

## **Per.spe.c.tive**

***noun***

1. A technique of depicting volumes and spatial relationships on a flat surface
2. A visible scene, especially one extending to a distance
2. The state of existing in space before the eye
4. The state of one's ideas, the facts known to one, etc., in having a meaningful interrelationship
5. The faculty of seeing all the relevant data in a meaningful relationship, mental view, or prospect

—*Dictionary.com*

### Caring for Caregivers: Shifting Perspective

When we begin the caregiving journey, the person who needs our care is no longer in familiar territory. Sometimes, as in the case of Alzheimer's or other dementias, they no longer appear to be themselves. We may find ourselves in a role-reversal with our parents—they always took care of us, and now we take care of them. Maybe they were never able to take care of us, and now they never will. If we're caring for a spouse or partner, they also relate to us differently. Perhaps they handled the finances or the social calendar, and all the things they once did landed squarely in our laps in addition to caring for their needs. We may be parenting grandchildren when we never expected to raise more kids, or we are caring for an adult child with a severe disability who is unable to live independently.

We may be motivated by love, duty, guilt, or purpose. We may have chosen the role, or it came unexpectedly. We may know the day is coming soon when we'll be called upon to provide care and are unsure how to prepare. Caregiving demands much of us, physically, psychologically, and emotionally, and can turn our world upside down. The focus of the relationship is on the person who needs our care, but the cost to the caregiver can be high. Moving beyond all the demands to make a place to care for ourselves, and the other caregivers in our lives, calls for a shift in perspective. I recently participated in a discussion group on strategies for positive aging. When we talked about the older adults in our communities who needed care, one group member remarked, "if the people we care for are invisible, imagine how invisible we are as caregivers."

Caregivers may not occupy the limelight at this time, but the numbers are significant. According to AARP's Public Policy Institute, 578,000 Wisconsinites cared for family members in 2013, providing 538 million hours of care. The economic value of that care was \$7,070,000; yet support for caregivers is only in the earliest stages. The required shift in perspective is challenging for caregivers, care recipients, and our communities. It's easy to be overwhelmed by the magnitude of the tasks—both caregiving and caring for the caregivers. Once we see the situation more clearly, we can make needed changes and provide more resources for caregivers. As a community, we can't manage without them.

If you need information or resources for family and other non-paid caregivers—including how to get support and care for yourself or another in the role of caregiver—contact the Dane County Caregiver Program. In addition to the resources available, we're working to make caregivers and their needs more visible.



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

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

#### Contact :

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[Website: https://aaa.dcdhs.com/](https://aaa.dcdhs.com/)

## Coping with Caregiver Guilt

Feelings of guilt are common in caregiving and can be overwhelming and disturbing. If not dealt with, these feelings can be physically, emotionally, and mentally harmful to you and those in your care.

People experience guilt for many reasons; past mistakes, unrealistic expectations of yourself, feelings of inadequacies, blaming yourself for other's actions, asking for help, taking time for yourself, or decision making (i.e., nursing home placement).

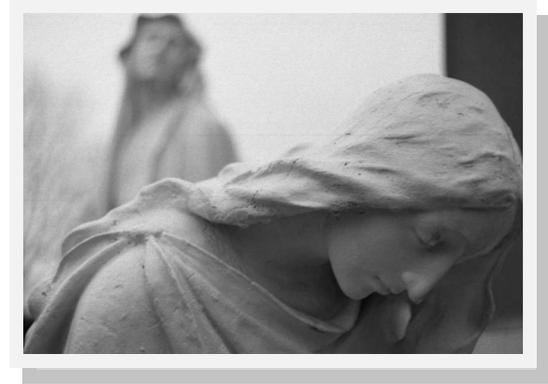


Photo by John Zimm

It is important to your mental and physical health to learn to manage and control guilt. Tips for dealing with these strong emotional reactions include:

- Get informed. Learn about the disability or disease and the care needed. Educating yourself will help you make sound decisions.
- Practice forgiveness. Nobody's perfect. Use past mistakes as a learning opportunity and know you are doing the best you can in a difficult situation.
- Talk about your feelings with someone who you trust, or write them down to express them. Talk to a professional if you are getting overwhelmed. Develop a support system (e.g., friends, relatives, professionals).
- Set priorities. Determine what is most important and don't sweat the small stuff. Be realistic about expectations for yourself and for the person in your care.
- Accentuate the positive. Focus on the good that remains and not on what's lost.
- Understand that it is okay to take care of yourself and take time just for you. By taking care of your own physical, emotional, and financial needs, you become a better caregiver.
- Keep a private journal of your successes. Remove focus on the negative.
- Recognize that asking for help is often a necessity and realize that most people want to be of assistance. Asking for help does not mean you are an inadequate caregiver.
- Learn to let go of the past and live in the present.

—Julie Sheahan  
Communications Coordinator, ADAW



*If you are caring for a loved one with a dementia diagnosis and are not sure where to begin, the Alzheimer's & Dementia Alliance of Wisconsin (ADAW) can arrange a care consultation. ADAW staff can work with you to define the problem and brainstorm ways to address it. Call 608.232.3400 or 888.308.6251 toll free in Wisconsin. For more information on ADAW programs and services, visit [www.alzwisc.org](http://www.alzwisc.org).*

### Caregiver Resources Online

#### **Compassion Fatigue: When Caregivers Go Beyond Burnout**

When caregivers burn out, compassion fatigue can follow. Unaddressed, it can result in abuse of the vulnerable care recipient. Proactive self care for the caregiver is one of the best ways to prevent stress from progressing to a dire state. (AgingCare.Com). <http://bit.ly/1Uv4j4o>

#### **7 Essential Dos and Don'ts for People Caring for Caregivers**

Sometimes, people need to be reminded how to react to the very fragile and stressed side of the caregiver by demonstrating support and avoiding what's not useful. (caregiver.com) <http://bit.ly/1MEagcL>

#### **Feeling Alone as a Caregiver? Build a Backup Team**

If your family members aren't comfortable or able to help with the hands-on tasks, consider requesting their hands-off assistance. Sometimes the best way to get help is to match people with a task they're most willing or able to do. (AARP) <http://bit.ly/1RNytt6>



Photo by Jane De Broux

**Sometimes a change of  
perspective is all it takes to  
see the light.**

*—Dan Brown*

## Social Events and Activities

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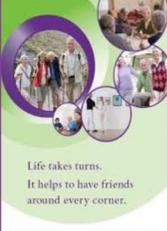
# Fitchburg Spry Society

- This program is intended for those experiencing early stage dementia, mild memory loss or cognitive impairment, and for family and friends of those affected.
- There is an interview that must be completed before attending the group. Contact Bonnie at (608) 203-8500 or [bnutt@alz.org](mailto:bnutt@alz.org) for more information or to complete the interview.
- The Spry Society will meet every FRIDAY AT 10.30AM. Participants may attend as many of the sessions as they prefer.

Starting in April, this free program will offer a comfortable way to have fun and socialize with others who are living with mild cognitive impairment. Enjoy the company of others while you participate in a variety of group activities ranging from group yoga and a brain-healthy nutrition seminar to a tour of both Camp Randall and Columbus' Sassy Cow Creamery!

**SAVE THE DATES!**

<ul style="list-style-type: none"> <li>April 1 - Kick-off (Fitchburg Senior Center)</li> <li>April 8</li> <li>April 15</li> </ul>	<ul style="list-style-type: none"> <li>April 22</li> <li>April 29</li> <li>May 6</li> <li>May 13</li> <li>May 20</li> <li>June 3</li> </ul>
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Life takes turns.  
It helps to have friends  
around every corner.









# Black Tie

# BINGO

A benefit for the North/Eastside Senior Coalition  
Friday, April 29, 6:00-9:30pm  
Cherokee Country Club, 5000 N. Sherman Avenue

**6:00-7:00**

**Social Hour**

cash bar  
hors d'oeuvres

**Silent Auction**

**Door Prizes**

**7:00-9:30**

**Bingo**

**Tickets**

\$40/single  
\$70 pair

Many thanks to our sponsors






Includes "2 for 1" fish fry coupon valid at Cherokee Country Club  
Advance sales only by April 15  
For details contact Trisha at 243-5252 or [trosbeck@nescoinc.org](mailto:trosbeck@nescoinc.org)



### LGBT Spring Social—Retired Colonel Sheri Swokowski

Thursday, April 28, 5:30 PM

The LGBT Senior Alliance presents Alliance Retired Colonel Sheri Swokowski, the highest-ranking out transgender army officer. She will share her lifelong struggle to be her authentic self, from her childhood in a conservative Wisconsin town, through her enlistment in the military as a young man, a distinguished military career, to where she is today.

Dinner will be served at 5:30 pm and the presentation begins at 6:30 pm. A \$10.00 donation is requested from those who are able, to cover the cost of dinner. Call OutReach at 608-255-8582 for more information.



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## ALZHEIMER'S STATISTICS WISCONSIN

### U.S. STATISTICS

Over **5 million** Americans are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$236 billion** in 2016, increasing to **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.



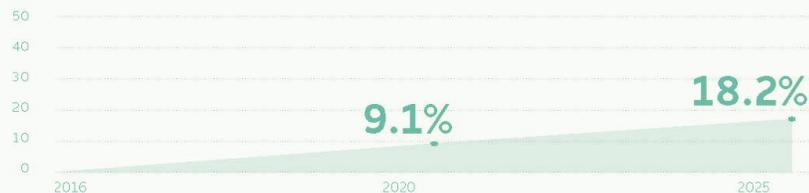
For more information, view the **2016 Alzheimer's Disease Facts and Figures** report at [alz.org/facts](http://alz.org/facts).

### 65+ Number of people aged 65 and older with Alzheimer's by age\*

Year	65-74	75-84	85+	TOTAL
2016	14,000	43,000	49,000	110,000
2020	17,000	48,000	50,000	120,000
2025	20,000	60,000	54,000	130,000

\* Totals may not add due to rounding

### Percentage change from 2016



### + Medicaid costs of caring for people with Alzheimer's, 2016

**\$706**  
MILLION

### # Number of deaths from Alzheimer's disease in 2013

- 6<sup>th</sup> leading cause of death in Wisconsin

**1,671**

### Number of Alzheimer's and dementia caregivers, hours of unpaid care, and costs of caregiving

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2013	190,000	217,000,000	\$2,698,000,000	\$122,000,000
2014	191,000	218,000,000	\$2,650,000,000	\$127,000,000
2015	192,000	219,000,000	\$2,679,000,000	\$131,000,000

**2016** | Alzheimer's Disease Facts and Figures

ALZHEIMER'S DISEASE IS THE **6TH LEADING CAUSE OF DEATH** IN THE UNITED STATES

**MORE THAN 5 MILLION** AMERICANS ARE LIVING WITH ALZHEIMER'S

**1 IN 3 SENIORS** DIES WITH ALZHEIMER'S OR ANOTHER DEMENTIA

IN 2015, MORE THAN 15 MILLION CAREGIVERS PROVIDED AN ESTIMATED **18.1 BILLION HOURS OF UNPAID CARE**

ALZHEIMER'S COSTS CAREGIVERS MORE THAN THEIR TIME

FAMILY CAREGIVERS SPEND MORE THAN **\$5,000 A YEAR** CARING FOR SOMEONE WITH ALZHEIMER'S

FOR SOME FAMILIES THIS MEANS **MISSING A VACATION**

BUT FOR OTHERS, IT MAY MEAN **GOING HUNGRY**

**EVERY 66 SECONDS** SOMEONE IN THE UNITED STATES DEVELOPS THE DISEASE

IN 2016, ALZHEIMER'S AND OTHER DEMENTIAS WILL COST THE NATION **\$236 BILLION**

IT KILLS MORE THAN **BREAST AND PROSTATE CANCER COMBINED**

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## The Aging and Disability Resource Center of Dane County (ADRC)

The ADRC offers free, unbiased information and assistance on resources and services for older people and adults with disabilities. Staff provides information to all callers regardless of their income, assets, age, or disability, and they help callers identify options, solve problems, and plan for the future.

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



**Call** (608) 240-7400

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

*Appointments are not necessary*

**Website:** [www.daneadrc.org](http://www.daneadrc.org)

**Email:** [ADRC@countyofdane.com](mailto:ADRC@countyofdane.com)

# Caring for the Caregiver Program

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## 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:

Jane De Broux

608-261-5679

[debroux.jane@countyofdane.com](mailto:debroux.jane@countyofdane.com)