## February 2024 CAREGIVER CHRONICLES BULLETIN

### Dane County Caregiver Program

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## Olders and People with Disabilities Are Not "Other." They Are Us or Future Us.

-Ashton Applewhite, Activist and Author



I've talked with hundreds of caregivers in my day-to-day work as Caregiver Specialist. I am frequently moved and often inspired by the love, sacrifice, and acceptance I hear on a daily basis from those providing care, sometimes in the face of overwhelming struggle. Some care for others because there is no one else who can do it. Some care for parents and grandparents while also caring for their children. Others care for a beloved spouse who no longer knows who they are, as in the case of some persons with Alzheimer's.

There are parents who have been caring for the severely disabled children who were never able to leave home and now those parents worry about who will continue caring for them once they, themselves, need care. There are grandparents raising their grandchildren because the children's parents are no longer able—they may have died, been incarcerated, are fighting addiction or struggle with physical and mental health issues. There are caregivers struggling with deep grief knowing that the end of their caregiving journey will be the loss of someone who means the world to them.

When caregivers reach out to the Caregiver Program, very few are marinating in self pity. They can be angry about the situation, depressed, stressed, grieving and in profound need of support but I also hear stories of love, joy, gratitude, and humor. In times when so much news and social media shows how people can be quite ugly with one another, I often witness the opposite. Seeing this very human part of life play out and watching people step in to help and support one another is the gift of work I am privileged to be able to do. Because I have a window into what caregivers face, I want to address a topic that I hope will bring more positive attention to and support for caregivers because our attitudes and any bias we might have influences how we prioritize support for populations in need.

### Ageism and Ableism Hurts Caregivers of All Ages

Caregiving is a truly intergenerational human activity. Families care for children, family members with disabilities or illness of all ages, and older adults. Ageism and ableism in our culture is harmful to everyone —and not all caregiving is viewed in the same light. In her September 2023 article for *The Cut*, "Raising Kids Is the 'Best Job in the World.' Why Is Caring for the Elderly the Worst?" columnist Kathryn Jezer-Morton put it this way: "Caring for young children is exhausting and it can push anyone to their limits, but caring for the elderly is categorically different . . . . Frailty in the old engenders a very different emotional response in most of us than does frailty in the young. It's all so difficult that for the most part we try not to think about it." But we can't afford not to think about it, and refusing to do so leaves caregivers without desperately needed resources and renders them invisible.

We divide people into categories to try to seek order in a chaotic world. Unfortunately, those with an agenda can choose to use those categories of difference to divide and conquer us in order to achieve an end. Aging is one of those categories that can be exploited for political goals or marketing goals. For example, politicians make arguments at times that attempt to frame funding sources as too scarce to support pre-school education, student loan forgiveness, and Social Security and Medicare. Playing on our emotions to gin up fear of resource scarcity can prod us into reacting with an us vs. them attitude.



Our culture has also taught us to fear aging and do everything possible to stave it off. This worry has become so pervasive that Gen Z (b. 1997 – 2013) believes it's "Aging Like Milk" (and that's not very well). It also inspires countless *OK Boomer* rants answered by olders punching down to a group with less perceived power. Throughout our lives we're bombarded by messages about how terrible it is to grow old and how devastating it is to be disabled.

According to activist Ashton Applewhite, an author at the forefront of the movement to raise awareness of ageism and dismantle it, "Ironically, people in aging services are not exempt. When your expertise lies in caring for olders at the most debilitated end of the spectrum—incredibly skilled, challenging, valuable work—it reinforces a view of aging as decline. Reconciling that deficit view of old age with what we hope lies ahead for ourselves is really hard to do."

### And where are family caregivers in all this?

How is it that 43.5 million family caregivers have been invisible for so long? Not enough studies exist yet to explain it but I have a theory. In part, cultural bias has made the process of aging and potential accompanying disability something to fear and hide. The resulting ageism and ableism presents obstacles to obtaining the resources needed by older adults and people with disabilities to age in place with dignity and for their families to assist them.

Caring for older adults and people with disabilities requires finding support from a larger community which often simply doesn't want to hear about it. Caregivers may feel isolated by the lack of public discussion on the topic. Our own fears regarding what happens to our bodies can keep us from normalizing all the experiences of our lifespan and robs us of the ability to offer our compassion and support. And the inherent grief in some caregiving situations requires acceptance that we are all mortal.

Truth resides in another quote from Ms. Applewhite:

All of us lucky enough to grow old—a privilege denied to many Black, Brown and disabled people—will age into impairment of some kind. As people in ageland are well aware, we age well not by avoiding chronic illness and disability but by adapting to them. These are powerful, generative processes that unite us all, and inform what it means to be human. Pretending otherwise sets us up to fail and pits us against each other.

–Jane De Broux, Caregiver Specialist Area Agency on Aging of Dane County

### **References and more information:**

The Cut, "Raising Kids Is the 'Best Job in the World.' Why Is Caring for the Elderly the Worst?" by Kathryn Jezer-Morton, September 18, 2023. Accessed 1.30.24

Generations Today January—February 2024, American Association on Aging, "Ageist? Ableist? Who, Me?" by Ashton Applewhite, January 18, 2023. Accessed 1.30.24.

CHAI The Center for Health and Aging Innovation Working Paper Series, "Ageism in the Family" by Stacey Gordon, DSW and Ernest Gonzales, Associate Professor, New York University, Silver School of Social Work. Accessed 1.30.24.





Memory Cafés to Resume & Caregiver Resource Fair Planned in Waunakee

After over two years of limited activity, Waunakee's Dementia Friendly Committee announces the Waunakee Memory Café will resume in March on the first Thursday, March 7. The Memory Café is a comfortable social gathering that allows people experiencing memory loss and their loved one an opportunity to connect, socialize and build new support networks. There is no fee to attend the Memory Café and refreshments are provided.

A Caregiver Resource Fair will be held on Tuesday, May 21. Mark your calendar for the Fair featuring agencies and organizations throughout Southern Wisconsin that provide assistance to caregivers. There is no fee to attend and refreshments are provided.

If you would more information about either event, please contact the Waunakee Senior Center at 608-849-8385.



www.careglverteleconnection.org



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Date	Time	Topic A LEADING VOICE FOR CAREGIVERS
All sessions will be available on Zoom and/or just the telephone. Your choice!		
Wednesday February 7	You may 11:00 am Eastern 10:00 am Central 9:00 am Mountain 8:00 am Pacific	Iog in or call in to participate Avoiding the Potholes of the Dementia Journey with Evalyn Greb, LCSW and Glenda Rogers Most of us have heard about the stages of dementia and how they impact the one for whom you are caring. This presentation will focus on how caregivers of persons with dementia can learn to steer through the rock yroad of dementia, armed with information and advice from other caregivers. You can be aware of what your future might hold and how to ease the journey Join us!
Monday February 12	1:00 pm Eastern 12:00 pm Central 11:00 am Mountain 10:00 am Pacific	Communicating with Health Care Providers in the Office with Zanda Hilger he family caregiver needs to ensure that the time in often short office visits is used wisely. Learn tools to focus on medical issues while building effective partnerships with healthcare providers **Sponsored by the North Central Texas Caregiver Teleconnection**
Thursday February 15	1:00 pm Eastern 12:00 pm Central 11:00 am Mountain 10:00 am Pacific	<b>Caregiving with Loss and Trauma with Dr. Natalee Oliver,</b> <b>DSW</b> Trauma does not go away because you are a caregiver. Join Dr. Natalee Oliver, DSW as she shares how compounding grief and loss from caregiving with trauma can evoke additional unexpected emotional responses. There is hope. Learn how to balance the multitude of reactions you may feel along with coping strategies.
Tuesday February 20	11:00 am Eastern 10:00 am Central 9:00 am Mountain 8:00 am Pacific	<b>Voices of Alzheimer's with Jim Taylor</b> Join Jim Taylor, President and CEO of Voices of Alzheimer's as he describes his journey of being a caregiver to his wife Geri since 2012 and the rewards and "burdens" he has experienced along the way. He will also share how out of this journey, he formed his non-profit organization, Voices of Alzheimer's, which has led the way in the creation of the Bill of Rights for People Living with Alzheimer's Disease. Come learn how sharing your story can make a difference.
Thursday February 22	11:00 am Eastern 10:00 am Central 9:00 am Mountain 8:00 am Pacific	Vida saludable para su cerebro y cuerpo: consejos de las últimas investigaciones con Maxine P. Vieyra Durante siglos, hemos sabido que la salud del cerebro y del cuerpo están conectadas. Pero ahora, la ciencia puede proporcionar información sobre cómo tomar decisiones de estilo de vida que pueden ayudario a mantener su cerebro y cuerpo saludables a medida que envejece. Únase a nosotros para aprender sobre la investigación en las áreas de dieta y nutrición, ejercicio, actividad cognitiva y compromiso social, y use herramientas prácticas para ayudarlo a incorporar estas recomendaciones en un plan para un envejecimiento saludable.
Wednesday February 28	11:00 am Eastern 10:00 am Central 9:00 am Mountain 8:00 am Pacific	The Importance and Benefits of Eating Healthy While Caregiving with Elliot M. Sklar, PhD and Lucy Barylak, MSW Caregivers often put their nutritional needs last, leading to changes in body weight and potential health issues. This program will focus upon the importance of nutrition for caregivers and care recipients alike. We'll discuss basics – like hydration and electrolytes, research on diet and brain health, time- saving tips, and what to look for in prepared foods.
	ELLMED TTABLE FOUNDATION	A program of the WellMed Charitable Foundation Register online at www.caregiverteleconnection.org or call 866.390.6491 Toll Free



Additional Dates: (Location: TBD)

May 11, 2024 July 13, 2024 September 14, 2024 November 16, 2024

### Monthly MIPPA Moment: February is Cancer Prevention Month

MIPPA (Medicare Improvements for Patients and Providers Act) has a goal of educating older adults on Medicare's cost-saving benefits &

National Cancer Prevention Month is observed in February to raise awareness about the importance of cancer prevention. Every year, over one and a half million Americans are diagnosed with cancer. Individuals age 60 and over make up over two-thirds of all newly diagnosed patients. Early detection of cancer can mean less extensive treatment, more treatment options and better chances of survival. Medicare pays for certain preventive health care services and screening tests used to help find cancer before you have signs or symptoms. Medicare covers the following cancer screenings at 100% when a participating provider provides the service:

- Breast Cancer annual screening mammograms and 3D mammograms for women age 40 and older.
- Cervical/Gynecologic Cancer 1 Pap test and pelvic exam every 24 months, or every 12 months if you are at high-risk for cervical or vaginal cancer.
- Prostate Cancer digital rectal exams and prostate-specific antigen blood tests once every 12 months for men age 50 and over.
- Colon Cancer colonoscopy once every 6 years for those not considered high-risk, or once every 4 years after a previous flexible sigmoidoscopy, and once every 24 months for those at high risk of colorectal cancer.

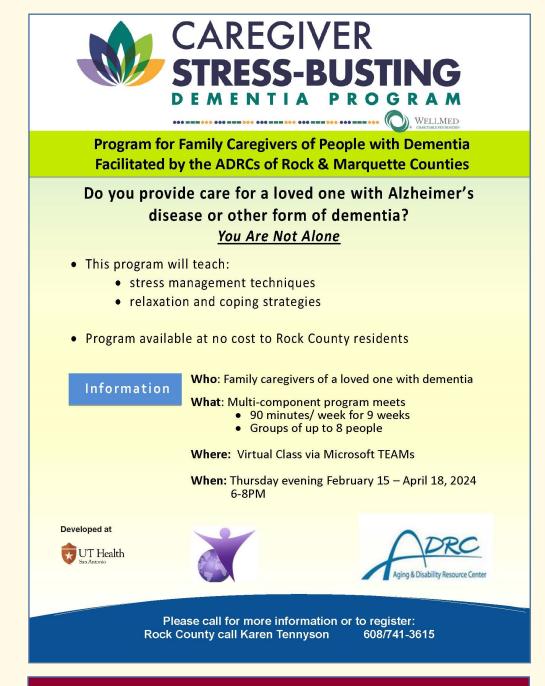
Visit the Medicare <u>website</u> or call 1-800-MEDICARE (1-800-633-4227) to learn more about its coverage of cancer screenings To find more information about Medicaid and the various programs in Wisconsin you can look at the Wisconsin Department of Health Services website at https://dhs.wisconsin.gov/ medicaid/index.htm. To determine if you qualify for Medicaid coverage, apply at access.wisconsin.gov or call your local Medicaid Agency.

In Dane County that is the Capitol Consortium 1-888-794-5556.

For more MIPPA Program information, call MIPPA Program Specialist, Leilani Amundson, at 608-240-7458.

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# **CAREGIVERS NEEDED!**

Idy Title: Barriers to Deprescribing

This study has received clearance from the University of Oklahoma Institutional Review Board (IRB #:xxxxx)



### Purpose of Study:

Research shows that some medications have harms that outweight the benefits,

especially for individuals with Alzheimer's disease or related dementias (ADRD). We want to understand how caregivers make decisions about their loved one's medications.

### Interested in Participating?

- Are you an unpaid caregiver (18 years or older) of an older adult with ADRD?
- Do you help the older adult make decisions about their health and medical care?
  - Do you have knowledge that the older adult is actively taking 1 or more of the
  - following medications:
  - benzodiazepines
  - antipsychotics
  - psychotropics
  - antidepressants
  - anticholinergics



COLLEGE OF ALLIED HEALTH CENTER



### Eligible and willing participants will:

- Participate in a 30 minute virtual interview session with the principal investigator and/or research mentor regarding your caregiving roles, knowledge, and barriers you may face.
- Receive a \$25 Amazon Gift Card as our gratitude for your time after completing the 30-minute interview session.

### Questions? Interested in Participating?

Please email the study coordinator or scan this QR code to learn more about this study and complete a brief screening survey



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