Caregiver Chronicles

March 2019



AREA AGENCY ON AGING OF DANE COUNTY 2865 N SHERMAN AVE, MADISON, WI 53704 608-261-9930

 $\underline{\mathsf{H}\,\mathsf{T}\,\mathsf{T}\,\mathsf{P}\,\mathsf{S}\,:\,/\,\,\mathsf{A}\,\mathsf{A}\,\mathsf{A}\,.\,\,\mathsf{D}\,\mathsf{C}\,\mathsf{D}\,\mathsf{H}\,\mathsf{S}\,.\,\mathsf{C}\,\mathsf{O}\,\mathsf{M}\,/}$



Life has many ways of testing a person's will, either by having nothing happen at all or by having everything happen at once.

—Paulo Coelho

Caregiver Chronicles

Caregivers Make News

O n February 19, my email inbox and social media accounts lit up with excitement about Governor Evers' Caregiver Taskforce Executive Order (see the official document on pages 6 and 7). In recognition of caregivers' critical importance to allowing older adults to stay in their homes and communities, the order's purpose is to "recognize, value, and celebrate the work of caregivers across the state of Wisconsin." According to the Wisconsin Aging Advocacy Network (WAAN), the task force will "bring together essential stakeholders from the Governor's administration, the legislature, those providing care and those receiving care, employers, and other key members who will inform the work of this group (<u>click here</u> to read the WAAN press release).

On the heels of this announcement came news of the Credit for Caring Act's introduction, a bipartisan bill presented in the legislature by Sen. Patrick Testin (R-Stevens Point) to provide a \$1000 tax credit for caregivers in Wisconsin. You can listen to the Wisconsin Public Radio podcasts covering both events for details (page 4).

In other caregiver news, an historic anniversary sparked a first-ever National Day of Advocacy scheduled for March 13. Inspired by <u>Stonewall's</u> 50th Anniversary coming this June, LGBT elders from across the country will gather to speak directly with their senators and representatives about their needs as older LGBT adults (page 4). A priority will be to address the Older Americans Act, which provides \$2 billion in federal funding to states for "essential supports like caregiver respite, transportation, and home meal delivery." The law authorizing the act, which funds the National Family Caregiver Support Program, will expire on September 30, 2019. In a local project for LGBT advocacy, The Alzheimer's Association, ADRC, OutReach, and Madison Public Library will present a Community Forum on LGBT & Dementia at the Sequoya Branch of the Madison Public Library on March 7 (details page 9).

While news stories highlight the increasing prominence of caregiver issues in the state of Wisconsin, a number of local institutions and organizations continue efforts to expand awareness and reach out to the broader community. On March 16, the annual Solomon Carter Fuller Brain Health Brunch will address Alzheimer's disease in the African American Community. Presented by the Alzheimer's & Dementia Alliance of Wisconsin, the Wisconsin Alzheimer's Disease Research Center, and the Wisconsin Geriatric Center, the event features educational sessions, discussions, performances, and more (details page 10) and is free and open to the public. On March 29, NewBridge Madison presents the 14th Annual Multicultural Senior Wellness Fair with 12 free health screenings and 35 informational booths (details page 11). Call in advance to reserve your lunch meal.

Hopefully, positive news and supportive events like these give you more of the "recognition, value, and celebration" caregivers deserve as Governor Evers mentioned in his description of Executive Order 11. And here's hoping Spring really is just around the corner!



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

608-261-5679 debroux.jane@countyofdane.com



Caregiver Role an Unexpected One?

The theme I've been hearing lately is one of overwhelm. Caregivers, coworkers, parents, and older adults have all had to slow down and cope with what nature has thrown our way this Winter. Snow removal begins to feel like an insurmountable chore for some and, coupled with record frigid temperatures and ice, just going about our daily lives has become more hazardous. Falling is more likely and more dangerous. A stalled car could mean exposure to elements and travelers need to be prepared. More careful planning is required for slower commutes, closures, and cancellations, and we need to be more mindful than ever of what our vulnerable populations need to be safe. When the cover photo of this issue appeared in my sister-in-law's facebook feed recently, I thought it illustrated perfectly just how I've felt at times this season—trapped, buried, and like shoveling my way out was going to take more energy than I had to give.

The resulting storms from the polar vortex also provided an excellent opportunity to understand more about what it means to live with challenges some caregivers and their care partners face. Just last Fall I was able to travel easily with few impediments, and I didn't have to plan so much for proper equipment, maintenance of my vehicles, or my wardrobe. I just took for granted I could zip here and there, getting what I needed when I needed it. I wasn't exhausted all the time. My commute took less time and I could easily get fresh air and exercise outdoors. I didn't have to bundle in layers and don cleats just to walk my senior dog to the corner, or rake my roof to prevent ice dams.

The twilight zone we enter into during the most severe winter weather is a fair analogy for what happens when a person who was able and mobile suddenly is not. The most basic activities of our lives are impacted and so much is totally beyond our control. We cannot influence the weather, nor can we prevent growing old, becoming ill, or having an accident. For caregivers thrust into the role suddenly, the adjustment can be a rough one. When an event occurs that forever alters the capabilities and personality of their care partner, then life, as they knew it, will never be the same. Of course it doesn't necessarily mean the end of a good life for either the caregiver or the care recipient, but the initial adjustment can be extremely difficult. There may be tasks that now require assistance, chores that need to be done by someone else and, in certain cases, the care partners may need to acquire a new way of communicating or relating to one another. A life once lived with spontaneity may now require significant planning—but it can be done with help and support.

Dane County's Caregiver Program is an important resource for those who suddenly and unexpectedly find themselves in the role of caregiver. National Family Caregiver Support Program funds, distributed in Dane County as Caring for Caregivers grants, can provide help with respite care, supportive home chores,

transportation, and adult day care along with supplemental services like personal emergency response systems, small home modifications, and other assistive devices. I work with case managers at Dane County senior centers

and coalitions to connect with community resources that benefit both caregivers and care recipients, and refer caregivers to the Aging and Disability Resource Center for a wide variety of resources and supports. If you are feeling overwhelmed, trapped, and unsure of what to do next, the Dane County Caregiver Program can help.

Although it doesn't feel much like it now, Winter ultimately yields to Spring. An overwhelming caregiving role can become manageable, too.

Yes, there's a person in there!



photo by Jane De Broux

—Jane De Broux

Online Resources

Listen to the Podcasts

State Capitol Report: Evers Launches Task Force On Caregiving

https://www.wpr.org/state-capitol-report-evers-launches-task-force-caregiving

WPR, The Morning Show

Monday, February 25, 2019, by Chris Malina, Program Host: Kate Archer Kent

"Wisconsin Governor Tony Evers recently signed an executive order aimed at establishing a statewide task force on caregiving. We hear what the governor is looking to accomplish with the move, and also hear from the chairs of the Wisconsin Family and Caregiver Support Alliance about what they believe would best help caregivers in the state."

New Bill in Wisconsin Legislature Would Provide Tax Credit for Caregivers https://www.wpr.org/new-bill-wisconsin-legislature-would-provide-tax-credit-caregivers WPR, Central Time

Thursday, February 28, 2019, by J. Carlisle Larsen, Program Host: Rob Ferrett

"A bipartisan bill introduced in the state Legislature would provide a \$1,000 tax credit for caregivers in Wisconsin if it's passed by state lawmakers. We talk to a state Senator and activist about the bill and their goals for the legislation."

* * *

A Day of Advocacy Decades in the Making

https://www.sageusa.org/a-day-of-advocacy-decades-in-the-making/

SAGE (Advocacy & Services for LGBT Elders) Posted January 4, 2019

"Fifty years ago this coming June, LGBT elder pioneers started the fight for LGBT equality at the Stonewall Inn in New York City. As the nation nears the 50th anniversary of this watershed moment for the LGBT movement, SAGE and LGBT elders from across the country will gather in Washington D.C. for SAGE's first-ever National Day of Advocacy on March 13, 2019."



Connecting People with the Assistance They Need Open 7:45 am—4:30 pm Monday through Friday

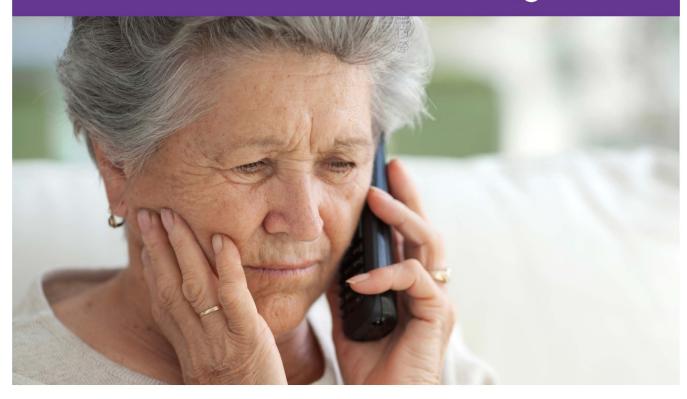
Call (608) 240-7400

Visit the ADRC office:

2865 N. Sherman Ave., Madison

Website: www.daneadrc.org

alzheimer's \mathcal{N} association[•]



Phone In Caregiver Support Group

Presented by: Alzheimer's Association Greater WI Chapter

LAST TUESDAY of each month 10am - 11am

REGISTRATION IS REQUIRED To register or learn more call 715.861.6174 or email at sbellefeuille@alz.org

Support Group Facilitator: Sharlene Bellefeuille, Outreach Specialist

Each registered participant will be contacted 2-4 days prior with the phone number and secure access code for each call.

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®



EXECUTIVE ORDER #11

Relating to the Creation of the Governor's Task Force on Caregiving

WHEREAS, caregivers and the direct care workforce provide critical services that promote the wellbeing and enhance the quality of life for thousands of Wisconsinites;

WHEREAS, the direct care workforce is facing a shortage that negatively impacts the ability for Wisconsin families to obtain the care they need;

WHEREAS, a significant number of caregiving positions go unfilled each year, leaving individuals in need of care with less access to care;

WHEREAS, people across Wisconsin are providing care to their friends and family members;

WHEREAS, Wisconsin's caregivers should be recognized and celebrated for the services they provide to some of Wisconsin's most vulnerable populations;

WHEREAS, it is increasingly difficult for providers to staff and maintain a consistent team of caregivers, placing stress on residential care and nursing home facilities;

WHEREAS, all Wisconsinites who depend on caregivers should have access to affordable, quality care that allows them to live with dignity and respect; and

WHEREAS, the state of Wisconsin can and must do more to support all types of caregivers and the families and individuals they serve.

NOW, THEREFORE, I, TONY EVERS, Governor of the State of Wisconsin, by the authority vested in me by the Constitution and the Laws of the State, hereby order the following:

1. Establish the Governor's Task Force on Caregiving under Section 14.019 of the Wisconsin Statutes. The task force shall be staffed by the Department of Health Services with technical assistance provided by the Department of Workforce Development as needed. The Governor shall appoint an individual to chair the Task Force and additional task force members as follows:

a. Members of the Legislature, representing each caucus;

b. At least one individual who receives caregiving services;

- c. At least one individual who provides caregiving services;
- d. At least one individual representing a provider who employs direct care workers;
- e. At least one individual from an organization providing respite services; and
- f. Such other individuals as the Governor shall appoint.
- 2. The Task Force shall be charged with the following:
 - a. Analyzing strategies to attract and retain a strong direct care workforce;
 - b. Supporting families providing care for their loved ones through respite services and other supports;
 - c. Assessing compensation and fringe benefits for caregivers including ways to make healthcare affordable for the caregiving workforce through employer-sponsored plans, Medicaid buy-in plans, or other health insurance coverage options;
 - d. Establishing one or more registries of home care providers and developing a plan to provide referral or matching services for individuals in need of home care;
 - e. Developing a plan to implement recruitment and retention programs to expand the pool of providers; and
 - f. Exploring and developing solutions, in collaboration with other relevant departments and agencies, to support and strengthen the direct care workforce, increase access, and improve the quality of caregiving in Wisconsin.



IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great seal of the State of Wisconsin to be affixed. Done at the Capitol in the City of Madison this eighteenth Day of February in the year of two thousand nineteen.

EVERS Governor



By the Governor:

DOUGLAS LA FOLLE

Secretary of State

Dane County

alzheimer's $\ref{eq:second}$ association[®]

OUR MISSION: To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

% Medicare beneficiaries with Alzheimer's / Dementia Diagnosis:

8.0%



Estimated Population with Alzheimer's / Dementia in 2020:

8.012

Estimated Population with Alzheimer's / Dementia in 2040:

17,143

238.5

Alzheimer's Association assistance in Wisconsin:

The number of Wisconsin chapter network service contacts in 2018:

Families can access our care and support services an unlimited number of times over their entire Alzheimer's journey by participating in support groups, education programs, calling the 24/7 Helpline, care consultations, safety services and accessing the care and support pages on our website.

alz.org I 24/7 Helpline 800.272.3900

LGBT & Dementia Community Forum



Thursday, March 7, 6-8 P.M.



Madison Public Library - Sequoya 4340 Tokay Blvd Madison, WI

You can also register with the Sequoya Library: 608-266-6385

Learn about Alzheimer's, dementia, memory loss and how it affects the LGBT community. Registration is preferred. Register online www.alz.org/scwisc or call 800.272.3900

alzheimer's \mathfrak{B} association[®]







Free and Open to the Public



Saturday March 16

8:30 am – 2:30 pm Wyndham Garden Hotel 2969 Cahill Main, Fitchburg

Solomon Carter Fuller Brain Health Brunch

Building awareness of Alzheimer's disease in the African American community

SCHEDULE OF EVENTS

- 8:30 am Registration
- 8:30 am 2:00 pm Health & Wellness Fair
- 9:30 am Free Community Brunch
- 10:15 am Keynote Address, "Double Jeopardy: The Curious Case of Health Disparities in the United States"
- 11:30 am Performance by "Amazing Grace" Chorus
- 12:00 pm Caregiver Strategies Panel Discussion
- 1:15 pm Healthy Food Demonstration









MASTER OF CEREMONIES **Rev. Everett Mitchell, JD** Dane County Circuit Court Judge Pastor, Christ the Solid Rock Baptist Church



KEYNOTE SPEAKER Carl V. Hill, PhD

Director, Office of Special Populations, National Institutes of Health

Details and registration online at adrc.wisc.edu/scf2019 or call (608) 232-3400



Caring for the Caregiver Program

AREA AGENCY ON AGING OF DANE COUNTY

2865 N. Sherman Avenue Madison, WI 53704



Phone: 608-261-5679 Fax: 608-283-2995 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:

Jane De Broux 608-261-5679 debroux.jane@countyofdane.com