

(608) 232-3400

alzwiss.org



Winter 2021-2022

CONNECTIONS



What is inside

Meet the Director - pg 2

Caregiving through a Cultural Lens - pg 4

A Wine to Remember - pg 6

After Caregiving - pg 10

Board of Directors

Carol Koby President

Ken Muth Vice President

Renee Rizzo Treasurer

Paul Pitas Secretary

Dr. Carey Gleason

Joyce Hastings

Dr. Perry Henderson

Dr. Vivian M. Larkin

April Weir-Hauptman

Tom Ramsey

John Stofflet

Staff

Jeff Hamm, MSW, CAPSW
Executive Director

Rose Kearney, MSW
Dementia Outreach Specialist

Barbara McKinney, MS, MBA
Diversity Outreach Specialist

Heather Moore, LPN, CDP
Dementia Outreach Specialist

Janet Wiegel, BS, PAC, CDS
Dementia Outreach Specialist

Mychela Burkhart
Marketing & Communications

Vicki Hodel
Executive Assistant

Becky Mulhern
Development & Communications

Mary Severson, CSW
Respite Grant Administrator

Lily Smith
Office Assistant

Thank You

COMMUNITY PARTNERS



BAILEY'S RUN
— VINEYARD & WINERY —

Bailey's Run Vineyard has been a supporter of ADAW since 2018, when they launched their annual 'Remember Me Red Run.' Owners Todd and Janet Kuehl's families have been greatly affected by Alzheimer's and dementia, so their motivation in providing funding for other families with a similar story is deeply personal.

Learn more about their story on page 6

Oak Park Place communities continue to show their support of ADAW throughout the year with fundraisers and their participation in our walk season. The staff's commitment to those with memory loss and their loved ones is incredible. They see the effectiveness of our programs and services daily and understand how important they are.



What is a Community Partner?

The meaningful work of this organization would not be possible without the support of our community. Our community partners include businesses, community groups, and other networks that want to make a collective difference and support ADAW's mission.

Involvement takes many forms, including collaborating on programs or events, raising awareness, or fundraising.

We appreciate all that they do in contributing positively to the many Wisconsin families touched by dementia.

MyStory

Jeff Hamm, ADAW Executive Director

I knew something was wrong when my dad phoned one night and reported, in a confused and anxious voice, that he thought he was in his apartment—but that it didn't look like his apartment.

He had been the maintenance person for his senior apartment complex for several years. A former detective, chief of police, clothing store manager, and EMT, dad became a tinkerer and fixer in later life, learning new basic skills in plumbing, heating, air-conditioning, and electrical work in his 70s.

His call scared me. Dad lived alone after mom's death a couple of years earlier. Only two children were in the area, one of my sisters and me, and we were both 45 minutes away. Should I jump in the car at 8:30 pm and drive to see him? Or could I just reassure him that he was in his home and safe? Did this relate somehow to the strange, paranoid stories about the other residents that he had begun spinning to me on Sunday mornings when we met for breakfast? I look back now with some guilt that, feeling overwhelmed with family and job, I did not ask more questions, did not go see him, but hoped that things would resolve.

As most of us know, progressive cognitive problems rarely just "resolve." I got a call weeks later from the apartment manager that dad had been walking into other residents' apartments in the middle of the night. He would have to leave—and soon.

I invite anyone grappling with the challenges of cognitive changes to reach out to our agency for assistance, guidance, education, and support. It is a gift and honor to be "your partner along the journey."

Suddenly my sister and I entered a spiral of failed facility placements, confinements at Mendota Mental Health Institute, hospitalizations, an ICU stay for life-threatening pneumonia, a miraculous recovery, and final placement at Badger Prairie Health Care Center. Along the way, health care providers and first responders used terms like "delirium" and "suspected vascular dementia," but I never insisted on knowing what they were talking about. Passive and reactive, I was carried along—and sometimes pulled under—by this fast-moving river of confusing and frightening behaviors, terms, and events.

I remember telling myself during this time that, if I ever had the chance, I would like to help spare others my confusing and scary experience with dad. So here I am—a long-time administrator and relatively new social worker, directing an agency whose focus is supporting persons who have been touched by dementia.

Dad died almost 11 years ago. I don't think about him every day, the way I did for the months after his passing. But the experience with his dementia informs my daily work.





Solomon Carter Fuller Brain Health Celebration

Caregiving through a cultural lens

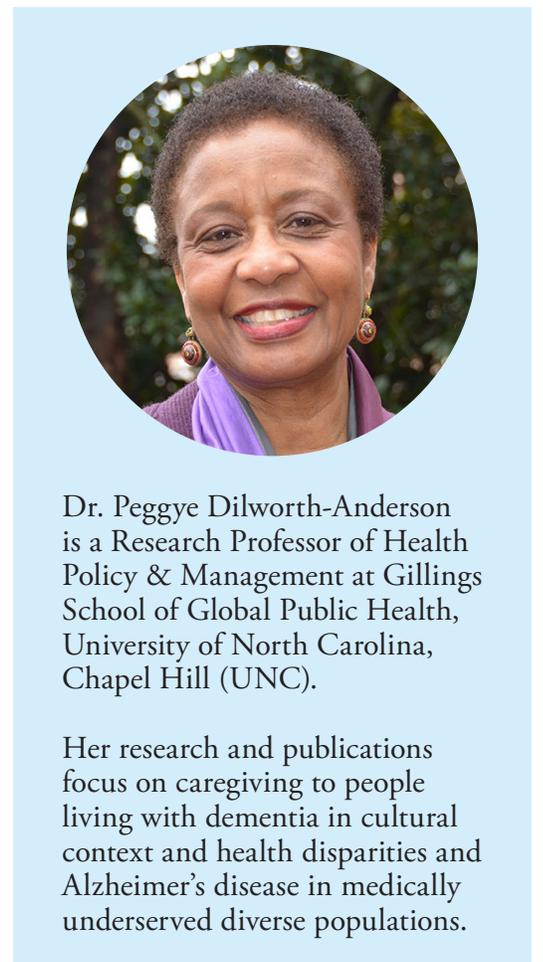
“Coping is central to the dementia caregiving journey,” reminded noted scholar Dr. Peggy Dilworth-Anderson during her keynote address for this year’s Solomon Carter Fuller Brain Health Celebration. So “use the coping strategies that are working for you.”

Those coping strategies can look different depending on the caregiver’s cultural background. Dr. Dilworth-Anderson explained that culture plays a critical role in understanding what dementia is, in interpreting dementia behaviors, and responding to dementia symptoms. Because culture affects caregiving, caregivers must get to tell their stories in their voice. “Where culture is ignored,” warned Dr. Dilworth-Anderson, “there is a greater chance of individuals not getting care or getting poor care.”

Research has suggested that five “domains of coping” are significant and influential for communities of color. These domains include “humor, faith, preempting conflict with the care recipient, seeking support, and disengaging.” When these or other coping tools are not working for care partners, Dr. Dilworth-Anderson told her audience, it is time to “hit the re-set button.”

“It may be that the plan needs to change,” she said. The support system may be too narrow and needs to expand outside the current caregiving circle. It may be necessary to confer with the medical provider about where their loved one is in the disease process—especially if there is a change. “Maintain awareness and be intentional in your caregiving role,” said Dr. Dilworth-Anderson.

Dr. Dilworth-Anderson’s presentation and the 11th annual Solomon Carter Fuller celebration were made possible by support from the Wisconsin Alzheimer’s Disease Research Center at UW-Madison.



Dr. Peggy Dilworth-Anderson is a Research Professor of Health Policy & Management at Gillings School of Global Public Health, University of North Carolina, Chapel Hill (UNC).

Her research and publications focus on caregiving to people living with dementia in cultural context and health disparities and Alzheimer’s disease in medically underserved diverse populations.

Be Social!

Online Programs

Meeting of Minds

Meets online weekly, Tuesdays 10:00 am - 11:30 am

A memory enhancement and support program to help maximize cognitive function and sustain quality of life for those with memory loss, Alzheimer's, or other dementias.

For more information contact: RKearney@alzwissc.org

Think Cap Café

Meets online weekly, Thursdays 11:00 am - 12:00 pm

Connect, engage and socialize with old friends, and new ones!

In partnership with NewBridge Madison's Diversity and Inclusion program

For more information contact: Barbara.McKinney@alzwissc.org

Virtual Memory Café

Meets online the 3rd Friday of each month

10:00 am - 11:30 am

For more information contact: RKearney@alzwissc.org

Love Me

Easy, breezy, cheesy,

geez we love cheese.

String cheese, cheddar, jalapeño,

cheese curds that squeak.

Cheese, cheese, wonderful cheese.

The ties that bind – too much cheese.

Glorious French that smells like feet –
it can't be beat.

Wine and cheese. Whoo! That's good.

In Wisconsin, it's almost law with apple pie.

You have to serve a piece of cheese.

If you please.

- Poem by the participants of
Meeting of Minds

In-Person Programs

Lodi Memory Café

Meets the 4th Friday of each month

1:00 pm - 2:30 pm

Reach Out Lodi: 601 Clark St,
Lodi, WI

For more information contact: RKearney@alzwissc.org

Prairie du Chien Memory Café

Meets the 3rd Tuesday of each month

10:00 am - 11:30 am

At Hoffman Hall: 1600 S. Wacouta Ave.
Prairie du Chien, WI

For more information contact: Heather.Moore@alzwissc.org

Portage Memory Café

Meets the 4th Thursday of each month

1:00 pm - 3:00 pm

At Portage Public Library: 253 E. Edgewater St.
Portage WI

For more information contact: Janet.Wiegel@alzwissc.org

Sauk City Memory Café

Meets the 3rd Thursday of each month

9:30 am - 11:00 am

At Sauk Prairie Community Center: 730 Monroe St.
Sauk City, WI

For more information contact: Janet.Wiegel@alzwissc.org

Reedsburg Memory Café

Meets the 2nd Friday of each month

10:00 am - 12:00 pm

At Fusch Community Center: 2090 Ridgeview Dr.
Reedsburg, WI

For more information contact: Janet.Wiegel@alzwissc.org

Richland Center Memory Café

Meets the 4th Thursday of each month

10:00- 11:30 am

At Woodman Senior Center: 1050 N. Orange St.
Richland Center, WI

For more information contact: Heather.Moore@alzwissc.org

Westfield Memory Café

Meets the 1st Wednesday of each month

10:00 am - 11:30 am

At Village Hall: 124 East 3rd Street,
Westfield, WI

For more information contact: Janet.Wiegel@alzwissc.org



From Left: Bailey, Janet and Todd Kuehl of Bailey's Run Vineyard in New Glarus, WI

A Wine to Remember

Over the summer, we sat down with Janet Kuehl of Bailey's Run Vineyard, which she co-owns with her husband, Todd in New Glarus. It had been a few months since we were last at the winery for the Remember Me Red Run in May. We were there now to hear more about how Alzheimer's and dementia play a role in their everyday lives.

The first person with a known diagnosis of Alzheimer's disease in Janet's family was her great-grandmother. She was a German immigrant whom Janet adored. "In 7th grade, I started learning German so I could connect with her in her native language," she said. A year later, when Janet was 13, her great-grandmother received a diagnosis of Alzheimer's disease, which she lived with for ten years.

As Janet grew up, she witnessed three of her great-grandmother's children receive a diagnosis of Alzheimer's, including Janet's maternal grandmother. Her father's mother was also diagnosed with dementia.

"I was always with my grandparents. We were at the lake house every weekend during the summer. When they were diagnosed, it was tough to lose that connection we once had."

Todd's family has been touched by the disease as well. His mother's father lived with Alzheimer's disease. "Todd's family was also very close, so this hit them hard."

Todd and Janet's grandparents were always at the forefront of their hearts and minds when developing plans for their winery. In 2015, they planted 1,500 vines on three lots. To honor Todd's late grandfather, the lot growing lacrosse grapes, known for making brandy, was named "Grandpa's Lot."

Their first grape harvest was in 2017. "When the time came to start making wine, we wanted to take it a step further and create a wine to honor our grandparents." They knew that they wanted to create a bottle where they could donate a portion of its proceeds to an Alzheimer's organization.

“Todd is the creative one,” says Janet. While struggling to come up with a name for this potential wine, Todd shot out of bed one night, proclaiming, “I got it! How about Remember Me Red?”

Every staff member at Bailey’s Run knows their story, and when you order a bottle, a glass, or just a sample tasting of Remember Me Red, they will tell it. “Almost every time, the customer will tell us they know someone with Alzheimer’s. It affects so many of us.”

As news of the Remember Me Red wine spread, the Alzheimer’s and Dementia Alliance of Wisconsin reached out to Janet and Todd. The idea of a fun run or race began to take shape. “In our hearts we knew it was a perfect pairing.”

Eighty runners took part in the inaugural Remember Me Red Run 5K in 2019. The event raised \$14,000 just in its first year. In 2020 even with all the pandemic challenges, they still raised \$14,000 with a virtual race.

2021’s event saw over 200 runners and over \$20,000 raised. “Go big or go home.” says Janet. She puts all her energy into this event, and it shows. “It has taken on it’s own life.”

The fundraising does not just stop at the race registrations. Remember Me Red Run is a day-long event. Guests bid on silent auction items and take part in a 50/50 raffle. The grounds are filled with people celebrating, remembering their loved ones, and donating to the cause.

Because of all the work she does in bringing awareness and light to Alzheimer’s and dementia, we asked Janet to be the Honorary Chair for the Green County Alzheimer’s and Dementia Walk in 2021. Without hesitation, she said yes! “I’ll do anything to help other families with the education and support needed to know you are not alone.”

“I know in our hearts that if our grandparents were still here today, they would be our biggest supporters, and hope they would be incredibly proud.”

- Janet Kuehl



Left: Runners at the start of the 2021 Remember Me Red Run 5K

Below: Janet with a bottle of Remember Me Red wine



Thank you for a memorable walk season!



2021 Alzheimer's & Dementia **W&LK** STEP FORWARD. GIVE HOPE



I Walk For...

Jamie Curles, 2021 Dane County Walk Honorary Chair

Hello, my name is Jamie Curles, and I have mild dementia. I have also been diagnosed with Bipolar and Schizoaffective Disorder. I have been involved with the Alzheimer's and Dementia Alliance of Wisconsin for approximately four years.

I first experienced memory issues in 2017 during a stressful period in my life. I suddenly found myself unable to remember my address and phone number. I would forget where I left my keys or my drink container. Sometimes I would forget why I was going somewhere or get lost going to places I had driven to many times before. About this time, my partner was dealing with serious health issues of his own. So I moved from Janesville to an apartment in Fitchburg to live with my son and his girlfriend. I have to admit it was scary knowing I couldn't remember common everyday things.

Now, I was not a stranger to the effects of dementia. My paternal grandmother and my father's older brothers all had experienced dementia. I grew up in Maryland and moved away from the east coast to live in Wisconsin when my children were very young. As time passed, my father began showing signs of dementia. He and his wife had to sell their home mainly because taking care of a house and yard became too difficult for them with their memory and mobility issues. They moved into a facility called Fairhaven in Sykesville, Maryland.

I would travel to visit whenever I could, and we kept in touch by phone, but I could see him slowly slipping away. On September 23, 2019, my dad passed quietly. He lost his battle with dementia.

Upon moving to Dane County, I joined the Second Baptist Church in Madison. The church regularly featured health-related speakers, and they hosted the All of Us touring bus, a research program funded

by the National Institute of Health (NIH). I chose to participate in a study. I was screened and offered my medical history to be used in future research for medical innovation. I was also put in touch with the ADAW and programs at the UW Medical Research Center.



I started attending Meeting of Minds, a program run by the ADAW for people with forms of mild cognitive impairment. We combine enriching brain puzzle activities with music, art, exercise, and healthy snacks. We met once a week at the Madison Public Library downtown. As I became more comfortable, I began helping with setup, greeting, and signing in participants. I gave out nametags, helped with word puzzles, and passed out snacks and art supplies.

The day my father passed away, I attended Meeting of Minds. I received emotional support from the Outreach Specialist, the wonderful volunteers, and my fellow participants. The ADAW, over the past four years, has helped me gain insight and build relationships. Thanks to programs such as Crossing Bridges, Meeting of Minds, Conversations support group, and the Memory Art Cafe, my quality of life has improved.

I now live in Rockford, IL, but since the COVID-19 outbreak, some of the programs have been available virtually over Zoom. For that, I am grateful!

Please join me today as we walk together and, virtually, raise money to help fund all the enriching programs available to people with Alzheimer's or any form of dementia, as well as the support programs offered to our caregivers.

I want to thank everyone for their participation and support. Let's make it possible to find a cure someday!

After Caregiving

Dementia brings many losses—future plans, cherished roles, shared memories, mutual relationships.

For care partners, the losses mount even more. The demands of care might mean giving up favorite pastimes, exercise, social connections, time for self, or regular healthcare. Some caregivers retire early, losing their work identity and workplace colleagues.

But what happens when caregiving ends? When a loved one goes to a facility or dies? How do care partners deal with this new loss?

These are the questions that led Lynn Gall, Wisconsin Department of Health Services Office on Aging, to bring together representatives of caregiver grant programs from across Wisconsin. Most of these staff worked with the federal National Family Caregiver Support Program (NFCSP) or the state-funded Alzheimer’s Family and Caregiver Support Program (AFCSP).

Gall asked them one question: What can we do to help caregivers transition to the next stage of caregiving and life?

Mary Severson, BS, CSW and Respite Grant administrator for ADAW, noted that this was a regular discussion among ADAW staff. Support groups become grief groups as caregivers return to their groups after the death of a loved one. Care partners who had placed their person in a facility find relief from daily care, but now struggle with guilt, loneliness, lack of direction, and sadness.

For Severson, who has an extensive background in hospice and grief work, these are natural and normal responses to loss and grief. As caregivers, “dementia just happens to us and changes occur without warning,” she said. “We don’t ask for it and we usually aren’t prepared for it.” Mary volunteered to work with a small group of colleagues from throughout the state to pull together materials that care partners might find useful “after caregiving.”

The result was a website of rich resources to help caregivers “maneuver through the emotional, legal, financial, and other life changes that come after day-to-day caregiving ends.” The site is currently hosted on the Greater Wisconsin Agency on Aging Resources (GWAAR) website (<https://gwaar.org/after-caregiving>).



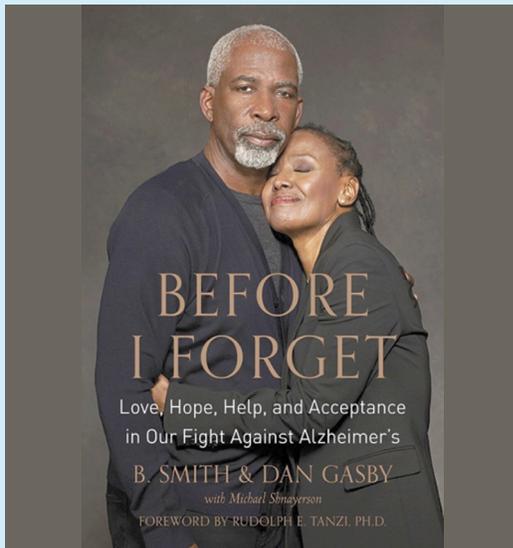
Some common themes emerged across the resources:

1. Take it slow. It takes time to accept the reality of the loss and process the pain of grief. Don't let others impose a timeline on you for feeling better.
2. Find places to express your feelings. The emotional pain that usually accompanies loss won't simply go away if ignored. Share what's going on with trusted family, friends, or professionals.
3. Get support. Rely on those who have helped you to this point. Stay connected with your support group or, if you have been going it alone to this point, consider joining a group now.

ADAW staff members can talk with care partners about their experiences of grief and loss and suggest resources, including support groups and counselors. Phone 608-232-3400 or email support@alzwisc.org.

What we are reading

Before I Forget: Love, Hope, Help, and Acceptance in our Fight against Alzheimer's by B. Smith and Dan Gasby.



The story of fashion model, restaurateur, cookbook author, magazine publisher, and food and style critic B. Smith, who was diagnosed with young-onset Alzheimer's disease at 63. Smith was committed to bringing her experience to the public, and especially to women of color, with the hope of increasing awareness and early diagnosis. The book interweaves Smith's story with crucial information about Alzheimer's symptoms, the disease progression, approaches to care, and promising research. A powerful and honest portrait of the dementia experience.

Gifts of Stock

If you are an investor, donating stock to ADAW makes good sense. Donating stock can potentially minimize taxes by getting a tax deduction for the stock's fair market value, avoiding capital gains tax on the stock's appreciation, and furthering ADAW's mission.

Stock transfers do not need to be complicated or expensive. If you wish to donate stock or mutual funds held in a brokerage account, give your broker the name of the stock you want to donate and the number of shares. Please have your broker call for current account information.

If you include the Alzheimer's and Dementia Alliance of Wisconsin in your plans, please use our legal name and federal tax ID.

Legal Name: Alzheimer's & Dementia Alliance of Wisconsin, Inc.
Address: 6314 Odana Road, Suite 4, Madison, WI 53719
Federal Tax ID Number: 39-1679333





6314 Odana Rd., Suite 4
Madison, WI 53719
(608) 232-3400
toll free (888) 308-6251

NON PROFIT ORG
US POSTAGE
PAID
MADISON, WI
PERMIT NO 260

**Dementia Outreach Specialists
are ready to help in your area!**

Dane County
(608) 232-3400

**Columbia, Sauk,
and Marquette Counties**
(608) 697-2838

**Crawford, Grant,
and Richland Counties**
(608) 723-4288

**Green, Iowa,
and Lafayette Counties**
(608) 232-3400

