

Summer has officially arrived! And with that comes the risk, especially for older adults, for heat-related illnesses. Take a look at the back cover for some safety tips for older adults this summer. Take care of yourself and your loved one and don't forget to hydrate!

In the last couple months, the caregivers who attend the Reedsburg Caregiver Support Meeting have been talking a lot about the books they read. Not that there's a bad time to read a book, but I think picking up a book while sitting on the porch watching the sun go down in the summer is an excellent time! Here are three books that I, myself and/or the caregivers would recommend:

- My Two Elaine's by former Governor Marty Schreiber a book about learning, coping and surviving as an Alzheimer's Caregiver
- The 36 Hour Day by Mace and Rabins is a classic book and highly recommended for caregivers of loved ones living with dementia. The book is a how-to manual on how to manage and solve problems caused by dementia.
- Dancing with Elephants by Jarem Sawatsky is a book that invites readers to not only acknowledge the elephant, but to dance with it: to find acceptance and joy amid <u>any</u> illness that has no cure.

If you are interested in any of the books mentioned (or many others), we have a Caregiver Lending Library where you can check out books and other items that can assist your caregiving journey. Give me a call or stop by the ADRC office! Additionally, if you have any recommendations for books that other caregivers would enjoy, please share that with me as well. Enjoy your summer and stay cool!



Sincerely, Marina Wittmann

Aging Program Supervisor
Caregiver Support Program Coordinator
marina.wittmann@saukcountywi.gov

The ADRC will be closed on Thursday, July 4



## Dear Kurt,

My mother appears to be having memory issues. I am wondering if it is dementia or Alzheimers.

Your question is a good one, but it does highlight a point of frequent confusion regarding brain issues. Dementia is an umbrella term indicating a loss of various aspects of brain function that interferes with daily life and has various causes and symptoms. Your mother may have dementia, but under that umbrella are the actual types of dementia, a wide array of diagnoses that do have some commonalities but at the same time are distinct and different. Alzheimer's is by far the most common form of dementia. This can be problematic if an individual has a different, less familiar diagnosis. Some examples are Frontal Temporal Dementia, Lewy Body Dementia, Vascular Dementia, Huntington's Disease, Jacob-Creutzfeldt Disease, Posterior Cortical Atrophy, dementia caused by alcohol or drug use, and individuals having more than one type or "Mixed Dementia".

Frequently in my visits, an individual or caregivers will state there is a "dementia diagnosis". Sometimes doctors do not pinpoint an actual type of dementia. While this is ok and can be a good starting point for discussion and planning, it is helpful to have a more specific diagnosis. Each type of dementia has a different causation and affects different parts of the brain in various ways. They also present differently. Someone with Alzheimer's may initially have deteriorating memory and word finding while someone with Frontal Temporal dementia will often have impulsivity as a first symptom. Posterior Cortical Atrophy often is initially noticed due to visual issues. Given this, the approaches to the person with the diagnosis may be significantly different. A consultation with myself as the Dementia Care Specialist may be helpful, but we are not clinicians. Talking to your doctor is the first step in pinpointing a diagnosis. They may be comfortable with this, or they may want to refer the patient to a neurologist or memory care clinic for evaluation. You can ask your doctor about this option. There is no one roadmap, but asking questions and being open to available information and diagnostic services can improve the quality of life for all facing the challenges of dementia.

Sincerely, Kurt

#### Do you have questions for Kurt?

If you have a question for Kurt, another caregiver probably has the same question. So ask away! Email Kurt your question: kurt.goeckermann@saukcountywi.gov Marina and Kurt will soon begin preparations for the 6th Annual Caregiver Boot Camp! If you would like to attend, help us plan. Where and when should we hold it in November? What topics do you want to learn more about? Have suggestions for a host facility?

Email or call us!

marina.wittmann@saukcountywi.gov
kurt.goeckermann@saukcountywi.gov

## Caregiver Support Meetings & Memory Cafe's

#### **General Family Caregiver Group**

- Riverwood Senior Living, Wisc Dells, Last Tuesday @ 10am | Contact Sue, 608-886-0873
- Woodman Senior Center, Richland Center, 4th Monday @ 10:30m | Contact Pam to register, 548-3954

#### **Veteran Specific Caregiver Group**

• **VA Clinic** in Baraboo, 3rd Monday @ 1:30pm | Contact Meghann Schmitt, 256-1901 ext. 12308 \*caregiver of enrolled veteran or enrolled veteran who is a caregiver

#### Parkinson's Specific Group

• First Congregational Church in Baraboo, 3rd Monday @ 2pm | Contact Geri Schoenoff, 356-3473

#### **Mental Health Specific Group**

- West Square Building, UW Extension Room, 3rd Monday @ 6pm | Contact Ted Hall, 1-608-301-5390
  - Virtual option available: <a href="https://us02web.zoom.us/j/84660758640">https://us02web.zoom.us/j/84660758640</a> \*for adults with a loved one who has symptoms of a mental health condition, including alcohol or substance use disorders

#### Dementia Specific Groups

- Maplewood in Sauk City, 4th Tuesday @ 3pm | Contact Theresa Grimes, 643-3383
- Virtual Morning Coffee Connect, Every Monday @ 10am | Contact Pam Kulberg, 548-3954
- Reedsburg Library, 3rd Wednesday @ 12pm | Contact Marina Wittmann, 355-3289

#### **Huntington's Disease Specific Groups**

• Virtual Huntington's Disease Groups, 3rd Tuesday @ 6:30pm (Caregivers), 2nd Tuesday @ 6:30pm (Young Adults, 16-35), 1st Saturday at 10:30am (Statewide) | Contact Deb Zwickey, 414-257-9499

#### **Memory Cafe's**

A safe space where caregivers and loved ones with dementia can socialize, listen to music, and have fun!

- Fusch Community Center, 2nd Friday @ 10am | Contact Kurt Goeckermann, 355-3289
- Reach Out Lodi, 4th Friday @ 1pm | Contact Penny, 592-4592

#### Alzheimer's Association Virtual Statewide Groups | call 800-272-3900 to register

- For Persons Living with Mild Cognitive Impairment, 2nd Wednesday @ 10am
- Family Caregivers for Loved One with Dementia Living at a Facility, every other Friday @ 10am
- Family Caregivers for Loved One with Frontotemporal Degeneration, 3rd Wednesday @ 6pm
- Family Caregivers for Loved One with Dementia in the Early Stages, 4th Tuesday @ 10am

#### ADRC Support for Caregivers | ADRC: (608)355-3289

ADRC: (608)355-3289

• Powerful Tools for Caregivers, Caregiver Lending Library, Respite Funding and more available!

Aging & Disability Resource Center

www.co.sauk.wi.us/adrc

## Hospice Provides Compassionate End-of-life Care

Learn about providing pain relief and comfort to patients, following their wishes before they die By: Deidre van Dyke, AARP; published October 14, 2021 / Updated May 17, 2024



In February 2023, after a series of hospital stays and battles with metastatic melanoma, a skin cancer which had spread to his brain and liver, former President Jimmy Carter entered hospice care. Like his wife, former first lady Rosalynn Carter, who suffered from dementia and died on Nov. 19, 2023, the former president elected to receive home hospice care instead of additional medical intervention. According to the Carter Center, the decision has allowed the former president to spend his remaining time with family at home.

#### What is hospice care?

Though the word "hospice" might trigger the notion of giving up on life, the goal is to give a person the best possible quality of life — emotional, physical and spiritual comfort.

"Dying isn't really the focus of hospice care," says Angela Novas, chief medical officer for the Hospice Foundation of America. "The focus of hospice is to live well for the remainder of your time, however long that is."

A multidisciplinary hospice team works together to care for the patient's medical, psychological and spiritual support. Team members can include the patient's personal physician, the hospice medical director, nurses and aides along with social workers, clergy and trained volunteers. Hospice can be provided at the caregiver's home, a hospital or a hospice facility.

#### Who pays for hospice?

The full cost of hospice services is covered by Medicare and Medicaid. "If your loved one isn't on Medicare or Medicaid, private insurance policies generally follow the Medicare model," says Davis Baird, director of government affairs at the National Association for Home Care & Hospice. There may be a copayment charge for some medicines or in-patient respite care.

Hospice is tied to a certain eligibility requirements. "You have to be certified terminally ill, meaning you have six months or less to live if your terminal illness runs its normal course," Baird says.

As we've seen from Jimmy Carter, in hospice care for over a year, you can continue to receive hospice care after six months, as long as you continue to meet eligibility req uirements, Novas says.

#### What is the difference between palliative care and hospice care?

"Hospice is a type of palliative care, but not all palliative care is hospice," Baird says.

Patients receiving palliative care have serious or chronic illnesses but can still be undergoing curative treatment for their condition. Under hospice, patients have either decided not to receive more treatment for their life-threatening illness, or there is no more curative treatment to be offered.

Under either system, patients and families will find interdisciplinary teams that work with them to alleviate not only the pain but also the stress of living with a serious or terminal condition. "And both systems excel at symptom relief," Novas says.

Entering hospice doesn't mean patients can't get medical care for other, unrelated conditions. For example, says Novas, a hospice patient who has pancreatic cancer won't receive more cancer treatment, but Medicare will still cover their treatment for glaucoma.

Patients who change their minds and want more curative treatment for their primary illnesses can revoke hospice at any time. "It's always the patient's choice," Baird says.

#### Roles of caregiver, hospice workers

"The role of hospice has always been to supplement the caregiving that is already being done by either family members [or] nursing home staff, if they're in a nursing home, or paid caregivers. Hospice does not take over that caregiving role. We supplement it," Novas says.

Article Continued...

Hospice doctors and nurses oversee medical care and manage pain and other symptoms. They'll also teach the family how to provide end-of-life care for their loved one. "What that can look like is a nursing aide coming three times a week for about an hour and a half each time on average[and] people get a visit by a registered nurse every week," Novas says.

Social workers and clergy provide support to both patient and family members to help with the emotional, psychosocial and spiritual aspects of dying. "What's hard is the family caregiver has been in the mode of taking care of the patient for so long ... and keeping that positive hope alive," says AARP caregiving expert Amy Goyer. "Now you are flipping and not fighting that fight anymore, but you are focusing instead in fighting the fight for their comfort and following their wishes."

Hospice will also take charge of ordering equipment. Durable medical equipment such as hospital beds as well as personal care and sanitation items, "that's all provided and delivered to the door," Novas says. "It's one less thing that [caregivers] have to do and it's one less thing that takes them away from focusing on the person that they're losing."

#### How to find high-quality care

A caregiver should research hospice agencies and identify the top choice or choices before this care is needed, experts say.

- Ask for recommendations from doctors, nursing homes, friends, family members and anyone who has knowledge of hospice care.
- Look at Care Compare on the Medicare site. Hospices are searchable by zip code, and you can compare ratings of different providers in your area. https://www.medicare.gov/care-compare/
- Visit hospice facilities or agencies in person to determine how you feel about the people you meet.

Hospice use for end-of-life care More than 1.7 million Medicare beneficiaries used hospice care in 2021, the most recent data available, according to the National Hospice and Palliative Care Organization.

Fifty-three percent were women, and most were over 75. Younger patients who died were less likely to use hospice care. Among Medicare patients who died:

Younger than 65: 25% were in hospice 65 to 74: 36% 75 to 84: 48% 85 or older: 61%

Source: National Hospice and Palliative Care Organization Facts and Figures, 2023

#### Prepare well in advance

Ahead of time, perhaps even years before a decision is necessary, talk with family members about their wishes for the end of their lives. Put it all in writing, perhaps in such legal documents as an advance directive, advance care planning or a living will.

"It is a huge comfort for a family caregiver to know what a loved one would want," Goyer says.

#### More resources

The Hospice Foundation of America has an Ask an Expert feature on its website where its experts answer questions and provide confidential guidance to patients and caregivers. The organization will also connect people to their local hospice organizations. https://hospicefoundation.org/Ask-HFA

The National Hospice and Palliative Care Organization has information on planning and preparation for hospice https://www.caringinfo.org/.

The National Association for Home Care & Hospice and the Center for Medicare Advocacy offer a booklet, "Questions to Ask When Choosing a Hospice Provider," available for download.

Sauk County Aging & Disability Resource Center provides listings of local agencies that provide hospice and palliative care. Additionally, ADRC Social Workers can provide options counseling for families to learn what options are available. Simply call the ADRC: (608)355-3289.



Check out AARP's Family Caregiving page for all things Caregiver: https://www.aarp.org/caregiving/

# Changes to Your Relationship Article from: Alzheimer's Association



As the disease progresses, your relationship with your spouse or partner who has Alzheimer's will change; however, your connection can still be rich and fulfilling. Spend time together in ways that bring you closer and help you relate.

#### **Changing Roles**

You may find yourself taking on a new role in your relationship as your partner's memory declines. The person with Alzheimer's disease may no longer be able to perform certain tasks, such as balancing the checkbook, doing the taxes, handling financial and legal matters and doing certain household chores. Making important decisions on your own may feel overwhelming.

Be prepared for these changes. Locate financial and legal documents, such as life insurance policies, property deeds and retirement accounts, soon after your loved one is diagnosed. Turn to family, friends, professionals or community resources for assistance, as needed.

#### **Intimacy**

You may be feeling enormous grief over the changes in your relationship. You are not selfish for experiencing these feelings. Given your partner's cognitive decline, you may no longer be able to have the same emotional or physical intimacy that you once shared.

It is typical that people with Alzheimer's disease experience changes in their sexual drive. Depression can cause a reduced interest in sex, as well as physical illness and some medications. It's also common for caregivers to lose sexual desire because of the demands of caregiving, the transition from intimate partner to caregiver, and changes in their partner's personality due to the progression of dementia. Do not feel guilty if your sexual attraction to your partner has changed. You can find new ways to connect with each other.

#### Family and friends

You may feel socially isolated because your family and friends may have pulled back from your relationship or you have little time to spend with them. Your family and friends may hesitate to spend time with you and the person with Alzheimer's because they worry about not knowing what to do or say. They also may not understand the behavior changes caused by the disease or might not be able to accept that the person has the disease.

activities they might be able to do together.

behavior changes caused by the disease or might not be able to accept that the person has the disease.

Take the initiative to contact family and friends and explain that while Alzheimer's disease has changed your lives in some ways, you value their friendship and support. Considering inviting a few friends or family members over. Let them know in advance of any physical or emotional changes in the person with dementia. Provide them suggestions about how to communicate with the person and what

### Overcoming Stigma

#### Article from: Alzheimer's Association

Facing stigma is often a primary concern of people living with Alzheimer's and their care partners.

Those with the disease report being misunderstood because of the myths and misconceptions others have about the disease.

Article continued.

After my diagnosis, I was overwhelmed by fear that made me want to hide. But out of that fear grew determination.

I wanted to learn everything I could about the disease and make awareness my cause."

-Phil G., Living with Alzheimer's

#### Why we need to fight Alzheimer's stigma

Stigma is the use of negative labels to identify a person with a disability or illness. Stigma around Alzheimer's disease exists, in part, due to the lack of public awareness and understanding of the disease, preventing people from:

- Seeking medical treatment when symptoms are present
- Receiving an early diagnosis or any diagnosis at all
- · Living the best quality of life possible while they are able to do so
- Making plans for their future
- Benefitting from available treatments
- Developing a support system
- Participating in clinical trials

Stigma and lack of awareness also impacts Alzheimer's disease research. The government funds Alzheimer's research at lower rates than other diseases, even when the cost of caring for Alzheimer's disease is significantly higher.

#### The experience of Alzheimer's stigma

Stigma and stereotypes are a significant obstacle to <u>well-being and quality of life</u> for those with dementia and their families. Here are some examples of the stigma you may experience:

- A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation.
- Relationships with family may change. Family members may not want to talk about the disease, perceive you as having little or no quality of life, or may avoid interacting with you.
- Others may approach your care partner to ask about you rather than asking you directly how you
  are doing.
- The reaction of some friends and family to your diagnosis may prevent you from seeking help from others.

#### Five tips to overcome Alzheimer's stigma

The following tips are based on the advice and experience of current and former members of the Alzheimer's Association National Early-Stage Advisory Group, which consists of individuals in the early stage of the disease who help raise awareness about the disease.

#### 1. Be open and direct.

- Engage others in discussions about Alzheimer's disease and the need for prevention, better treatment and an eventual cure. Engage with others like you on Alzheimer's Association boards.
- 2. Communicate the facts.
  - Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand Alzheimer's disease. Learn the facts about Alzheimer's and find an education program online or near you.
- 3. Seek support and stay connected.
  - It is important to stay engaged in meaningful relationships and activities. Whether family, friends or a support group, a network is critical. Find an early-stage support group near you.
- 4. Don't be discouraged.
  - Denial of the disease by others is not a reflection of you. If people think that Alzheimer's disease is normal aging, see it as an education opportunity. Here are some tips for helping family and friends adjust to your diagnosis.
- 5. Be a part of the solution.
  - As an individual living with the disease, yours is the most powerful voice to help raise awareness, end stigma, and advocate for more Alzheimer's support and research. Learn how you can make a difference in the fight against Alzheimer's.



# For Grandparents and Relative Caregivers



### **ONGOING VIRTUAL** SUPPORT GROUPS

#### BIRTH PARENT SUPPORT



A relaxed chat with other Wisconsin adoptive, foster, kinship, and/or guardianship parents to connect and feel supported. This group meets on the first Friday of the

COFFEE TALK



Open to any birth parents who have had a child placed for adoption, no matter what type of adoption or agency involved. This group meets on the second Tuesday of odd months at 6:30 PM.

#### ADULT ADOPTEES



Connect with other adult adoptees from around Wisconsin. This group meets on the second Wednesday of the month at 7:00 PM.

#### WAITING TO ADOPT



A welcoming space to discuss adoption-related questions, between evenings and daytime.

#### FOSTER PARENT SUPPORT



This group is designed to offer support to Wisconsin foster parents focused on various topics each month. This group meets monthly. Visit the calendar for details on time.

#### OPEN MIC TEEN SUPPORT



Designed for teens in foster, adoptive, kinship, and/or guardianship families to socially connect and discuss topics related to family dynamics. This group meets on the second Tuesday of the month at 7:00 PM.

#### TRAUMA INFORMED PARENTING



Designed for Wisconsin foster, guardianship caregivers with a high level of need due to complex trauma histories. This group meets on the third Monday of each month at noon

Date and times of groups are subject to change. Check the calendar of events on the Wisconsin Family Connections Center website for the most accurate schedule for each group. Registration is required to attend.

#### KINNECT RELATIVE CAREGIVERS OF CHILDREN



Designed for grandparents, uncles/aunts, siblings, or other relatives acting as the primary caregiver for children. This group meets on the last Thursday of every month at 11:00 AM.

#### **REUNIFIED PARENTS**



Designed for parents who have recently reunified, or are in the process of reunifying (transitioning to reunification within the next month). This group meets monthly on the first Wednesday at 6:30 PM.



## QUOTE OF THE ISSUE:

There is something magical about the way a sunset can make us feel at peace, grateful and alive all at once.

~Morgan Harper Nichols

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#### Sudoku Rules:

Fill in the blanks so that each of the nine rows, columns, as well as each of the nine 3x3 grids must contain one of each number 1-9. Color Mei

# How To Prevent Freezing & Falls



Your care recipient with Parkinson's may experience symptoms like freezing or problems with their vision. Freezing can make your care recipient feel like their feet are glued to the floor, which makes it hard to move around safely and can lead to falls. Freezing often happens when:

- » Walking through doorways.
- » Going up or down stairs.
- » Turning around in a circle or turning a corner.

#### Freezing can also happen when:

- » Waiting for their next dose of medication.
- » Walking in crowded places.
- » Walking in tight, enclosed spaces.



How To Prevent Freezing & Falls

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### 4 Ways To Help

Here are a few ideas you can try to help:

#### 1. Use Cues

- » Use verbal cues. Say "left foot, right foot, left foot, right foot" to tell them which feet to move to start walking again. If they shuffle their feet, say, "Take big steps" to prevent falls.
- » Use sounds. Clap or tap in a step rhythm or count out loud, so they can move to it.
- » Use imagination or visualization. Tell them to imagine a line they have to step over or are stepping between stones.
- » Keep them focused. Remind them not to get distracted by talking or multitasking when walking.

#### 2. Support Independence

Practice cues your care recipient can use on their own. For example, they can say aloud, "One step, two step, one step, two step". They can also try shifting their weight between their feet or moving another part of their body.

#### 3. Take Medications On Time

Taking medications on time can help keep movement symptoms under control. To help with this, you can support your care recipient to use:

- » Alarms or reminders on a smartphone or watch.
- » Written reminders in a schedule or planner.
- » A smart device like Amazon Alexa or Google Home.

#### 4. Change The Environment

- » Ensure furniture isn't too close together or too close to walls. This creates more open space for moving and turning around.
- » Remove loose rugs and floor clutter. This can help prevent falls or tripping.
- » Place strips of bright-colored tape on the floor to avoid a freezing episode. Place tape:
  - On the step of each stair so they know where to step.
  - On the floor of a doorway or in a hallway to help them place their feet when walking.
- » Ask the healthcare team about home equipment that may help them in freezing situations.



**Connected!** Call or Email Marina Wittmann

ADRC: (608)355-3289 marina.wittmann@saukcountywi.gov

4	2	7	5	6	1	8	9	3
9	6	8	3	2	7	5	4	1
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Solution for Sudoku

#### ADRC 505 Broadway St Baraboo, WI 53913

# sure to drink plenty of water and sports drinks with electrolytes so that you stay hydrated and decrease Tasty summer cocktails are definitely tempting, but remember: Alcohol increases dehydration. Make Seniors

Stay hydrated

Summer Safety Tips



the risk of heat exhaustion.

# 2 Dress smart

If you are planning on spending significant time outdoors on a hot day, dress appropriately. Avoid dark colored clothing and thick fabric to stay cool and fresh.



The middle of the day is when the sun tends of Dermatology recommends avoiding direct sunlight between 10 a.m. and 2 p.m. sun's powerful rays, the American Academy to be the strongest. To stay safe from the Beat the heat



5 Take precaution with medications

Medications can sometimes cause increased sun sensitivity. Be sure to know how your prescriptions may affect you before spending prolonged time in the sun.

# STORYPOINT Senior Living

# and has an SPF of 30 or higher.

3 Protect yourself