

CAREGIVER HANDBOOK

A Guide for Support



Sauk County ADRC
505 Broadway Suite 234
Baraboo, WI 53913
(608)355-3289
www.co.sauk.wi.us/adrc

ADRC
Aging and Disability Resource Center
of Sauk County

Your Bridge to Support

CAREGIVER HANDBOOK

So much goes into caring for a loved one. The Sauk County Aging and Disability Resource Center (ADRC) is a trusted source of information and resources for families, caregivers, and loved ones. This handbook will serve as a guide to what's available for family caregivers. For any questions, please contact the ADRC Caregiver Support Program any time: (608)355-3289.

If viewing this document electronically, you will find many links throughout the document. These links will be found in paragraphs and will be underlined. Simply click and be directed to the website!


If viewing this document on paper, please call the ADRC (608)355-3289 if you need assistance accessing any of the documents or websites presented in this guide.


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**Aging and Disability Resource
Center of Sauk County**

 505 Broadway
Baraboo, WI 53913

 (608)355-3289

 ADRCbaraboo@saukcountywi.gov

 www.co.sauk.wi.us/adrc

 www.facebook.com/adrcsauk/

 www.instagram.com/adrcsaukco/

This guide was created with inspiration from the ADRC of Brown County.

WHO ARE FAMILY CAREGIVERS?

Are you a son, daughter, relative, friend or neighbor who:

- Arranges medical appointments and provides transportation?
- Prepares meals or assists with grocery shopping?
- Helps with cleaning or laundry?
- Sets up medications to ensure safety?
- Checks in regularly to make sure your loved one is okay?
- Generally worries about your loved one's well-being?

Are you a spouse who:

- Has taken on duties such as cooking, bill paying, or chore upkeep that used to be done by your spouse?
- Must accompany your spouse to place they used to go alone?
- Assists with activities of daily living like bathing, dressing, or grooming?
- Feels unable to leave your spouse home alone?

If you answered “yes” to any of these, you are a family caregiver. It's easy to downplay what you do as just doing things for people you love. Yes, that's absolutely true – you do those things because you care for that person and their well-being. You provide assistance to that person who without that, might not be able to live in their own home. The ‘little things’ you do for them are the BIG THINGS that allow them to maintain their independence.

It is important to recognize and identify family caregivers because it opens the door to resources and support that can compliment care already being provided. The ADRC has supports for family caregivers such as respite funding, support groups, memory café's, online learning tools, educational workshops, caregiver lending library, Dementia Care Specialist program, and more! Maybe you don't need these services right now, but as Former First Lady Rosalynn Carter said, “There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers”.

Whether you are new to the caregiving role, or have been caring for a loved one for years, caregiving can take a toll on your physical, mental, and emotional health. The next page has a Caregiver Stress Quiz you can take to determine how well you are holding up to the added stress of caregiving. Taking care of yourself while caring for a loved one is difficult, but it's essential not only for your well-being, but so that you can be the best caregiver for your loved one.

CAREGIVER STRESS QUIZ

How well are you holding up to the added stresses of caregiving? This short quiz can help you determine your stress level. While this is not a scientific test, it can help you identify how you are managing caregiving stress. Keep in mind that everyone is different. You may have scored a “5” and still feel very stressed. The important thing is to remember that resources are available help you. It is well worth your time to find them.

	Never	Sometimes	Usually	Almost Always
I cannot get enough sleep.	0	1	2	3
I have conflicts with my family members.	0	1	2	3
I feel anxious.	0	1	2	3
I feel like I have no time for myself.	0	1	2	3
I worry that I am not doing a good job as a caregiver.	0	1	2	3
I feel depressed, trapped or resentful.	0	1	2	3

Scores:

0-7 You are managing pretty well.

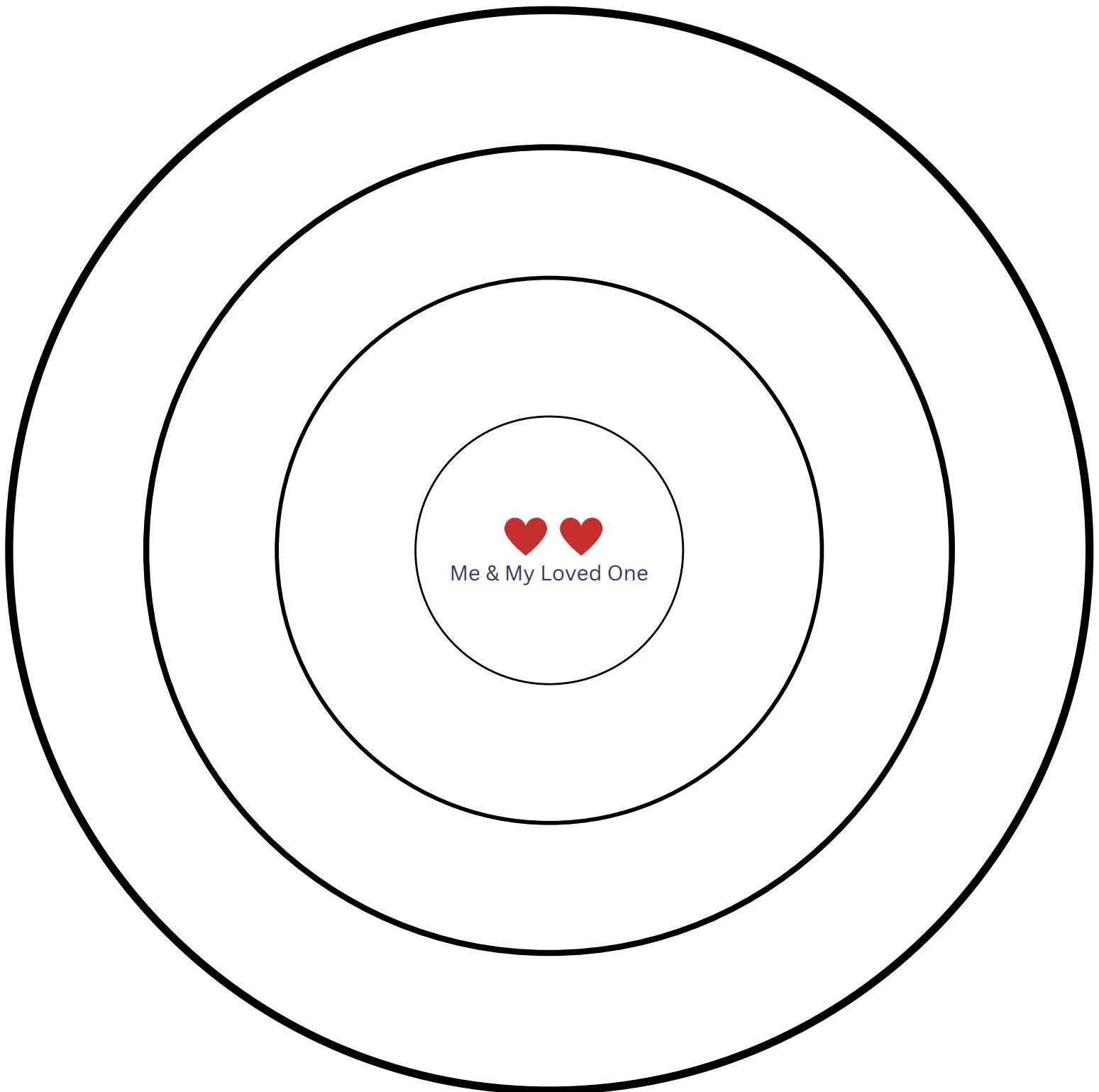
8-12 You should find additional support.

13+ You seem to have serious burnout. Take steps now to find support.

Caregiver Stress Quiz from www.standrewsseniorsolutions.com

WHO'S IN YOUR CIRCLE?

When thinking about care needs at home for your loved one, you might want to consider who is in your circle. Use the circle of care below to brainstorm who you could call on if you needed them. At the center will be you and your loved one. The next ring will include your family and close inner circle. Next will be your friends, family and neighbors that maybe have offered a hand if you ever needed it. Lastly, community and support groups should be included in the last ring. Think outside the box – church groups, social groups, former hobby groups, former coworkers, friends of friends, etc.



WHAT IS RESPITE?

Respite care, whether on a planned or emergency basis, is taking a short break from caregiving duties, and it allows the caregiver an opportunity to rest, refresh, and recharge. Respite can occur in the caregiver or care recipient's home or in a facility-based environment and it looks different for every caregiver. Respite might be signing up for that yoga class you've been putting off, going to a movie, having lunch with a friend you haven't seen in a while, or simply taking a drive while your loved one is being cared for. Taking care of yourself by taking breaks isn't something to put off – it's vital not only for your loved one's care, but for your own health.

FACILITY AND HOME-BASED CARE

In-Home Care

Home care, home health care and in-home care are all terms used for services brought into the home to assist individuals with daily care needs. Home care provides services needed so people can continue living independently in their homes. Care can range from tasks such as cleaning or meal prep all the way to skilled nursing care like help with bathing and personal cares.

Home care agencies provide a wide range of services including personal cares such as help with bathing and household chores such as laundry, among many other tasks. Sauk County ADRC houses an In-Home Care Guide (<https://www.co.sauk.wi.us/adrc/home-and-community-based-resources>).

Hiring a private worker is also an option for getting care at home. The ADRC has a worker-referral program called the Helping Hands at Home program. Workers on the list provide a wide range of services which you can hire and pay privately. The Helping Hands at Home list can be found here: (<https://www.co.sauk.wi.us/adrc/home-and-community-based-resources>).

Palliative Care

Palliative care is treatment to help the body feel better in body, mind and spirit while doctors also treat the illness. It can include care such as pain relief, counseling, and nutrition. It can also include learning about the illness better, talking about feelings, and deciding what treatment is wanted or not wanted.

Hospice Care

Hospice care is for people who are near the end of life, when a doctor believes they have no more than about 6 months to live. The goal is to help people feel better and get the most out of the time they have left. No treatment is given to cure the illness during hospice. The Sauk County ADRC houses a Palliative Care and Hospice Agency list (<https://www.co.sauk.wi.us/adrc/home-and-community-based-resources>).

Adult Day Care

Sauk County has one Adult Day Care provider – Reminisce Adult Day Services, located at RAMC Senior Life Center in Reedsburg. For more info about Reminisce, call (608)768-5815.

HIRING A WORKER

Hiring a worker to care for your loved one will come with a range of feelings and emotions. Feelings of anxiety, sadness, worry and guilt are common. You want to find the right person for you and your loved one, and that may take some trial and error. Thinking about the individuals in your circle is a great place to start. If you utilize any of the resources for in-home care mentioned earlier, you may not know the person whom you are trying to hire for care. Below are some tips to think about as well as questions to ask a potential worker. If a worker isn't a good fit for you and your loved one, do not give up and keep trying!

Tips for hiring a care worker:

1. Trust your instincts. Remember that this person will be coming into your or your loved one's home and you should never feel unsafe.
2. Develop a list of exactly what jobs you want and an idea of how much you are willing to pay the individual.
3. Start with a telephone interview. Describe the jobs you have in mind and be clear about your expectations. Ask about hours and wages. Also, ask if there will be any extra costs (like mileage or gas). Ask them about their previous job experiences. During the call, do NOT give too much personal information – like your last name or address.
 - a. If you don't think the individual is a good fit, it is not necessary to schedule a face-to-face interview.
4. Schedule a time to interview. It can be a good idea to have someone with you (like a neighbor or family member) during the interview. They will make you feel more comfortable and will be able to give you their perspective.

What questions to ask during the interview:

- What is your experience?
- What is your current employment situation?
- How flexible is your schedule?
- What kinds of special training, if any, have you had?
- What are your salary requirements and is it negotiable?
- Would you ever have any occasion to bring someone with you?
- What do you like about this type of work?
- Do you have reliable transportation?
- Would you agree to a trial period?
- What would you do if the person you were caring for had a medical emergency?

FINANCIAL RESOURCES

Medicaid

Wisconsin Medicaid is a joint federal and state program that helps residents get high-quality health care coverage, long-term care, and other services that promote physical and mental health, and well-being. There are many types of Medicaid programs with different eligibility criteria. ADRC Information & Assistance Specialist Social Workers can answer questions about Medicaid as well as screen individuals for the Long-Term Care programs like Family Care and IRIS.

National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) provides respite, information, support and resources to family caregivers. If eligible, caregivers can receive limited short-term respite funding for chore services, personal cares, homemaker tasks, or general companionship. Funding is also available to purchase items that assist caregivers such as assistive devices, minor home modifications like grab bars, supplies like incontinence supplies and more. NFCSP is available in every county in Wisconsin. Contact the Sauk County ADRC for information: (608)355-3289.

Alzheimer's Family and Caregiver Support Program

The Alzheimer's Family and Caregiver Support program provides funding for eligible caregivers to pay for respite services and goods for a loved one who is living with dementia or Alzheimer's. AFCSP is available in every county in Wisconsin. Contact the Sauk County Human Services department for information on AFCSP: (608)355-4200.

Respite Care Association of Wisconsin

The Respite Care Association of Wisconsin provides respite care grants, respite care provider training, and a respite care registry. Respite care grants provide financial support for family caregivers to hire respite workers to provide care as well as goods and services that compliment care such as snow removal, lawn care, etc. Visit the Respite Care Association website for grant information (<https://respitecarewi.org/grants/>).

Still Working? – Employee Assistance Program

If you or a family member are working, your workplace may have an Employee Assistance Program (EAP) that provides counseling, life coaching, medical advocacy, and more. To find out if EAP is available, contact the Human Resources Department at your place of work.

Diagnosis-Specific Grant Funding Opportunities

American Parkinson Disease Association

American Parkinson Disease Association: Offers a patient aid scholarship program designed to provide financial support to people with Parkinson Disease (PD) and their families. Approved applicants will be eligible to be granted up to \$500 per calendar year (January – December). Funds are limited and will be awarded on a first come basis. The application can be found here: [APDA Application](#) or call the ADRC for a copy.

FINANCIAL RESOURCES

More Diagnosis-Specific Grant Funding Opportunities

Alzheimer's/Dementia Diagnosis

Home Care Recharge Respite Grant: For those with a diagnosis of Alzheimer's or related dementia, currently living at home and have a financial need, emotional need, and who need access to social support. Find grant information here (<https://wearehfc.org/care-grants/>) or call the ADRC for a copy.

ALS Association of Wisconsin Chapter

Brain Trinastic Memorial Grant Program: Assists with the needs of those individuals living with ALS. The Chapter does not receive federal or state funding. The Grant Program is solely funded through private donations, memorials, Chapter sponsored and Community/Family events. The grant application is found here: [ALS Association of Wisconsin Chapter](#) or call the ADRC for a copy.

Association for Frontotemporal Degeneration

FTD imposes a severe economic burden on persons diagnosed and their families. AFTD offers Comstock Grants for respite care, quality of life, and travel grants as direct assistance to people in the FTD community. FTD grant information is found here (<https://www.theaftd.org/living-with-ftd/resources/comstock-grants/>) or call the ADRC for a copy.

Blake Matthew Foundation

The Blake Matthew Foundation provides compassionate support for individuals facing mental health challenges by removing both financial and accessibility barriers to care. They offer wellness grants for therapy sessions and holistic treatments. Information on the grants can be found on the Blake Matthew Foundation for Mental Health website (<https://www.blakestinman.com/>).

Veterans

If you or your loved one are veterans, are you connected with the Sauk County Veterans Service Office (VSO)? The VSO is a liaison between veteran benefits and those who may be entitled to them. The Sauk County Veterans Service Office is located at the West Square Building, 505 Broadway Room 102, Baraboo and can be reached at (608)355-3260.

Additionally, the Department of Veterans Affairs has programs for family caregivers, called the "Program of Comprehensive Assistance for Family Caregivers". If eligible, families can receive education, training, mental health counseling, a monthly stipend, free legal and financial advice, and more. Program details can be found here (<https://www.caregiver.va.gov/>).

Alzheimer's Association

The Alzheimer's Association is an excellent resource if you are caring for a loved one who is living with Alzheimer's or any dementia. The Alzheimer's Association has support for caregivers and loved ones including virtual support groups and educational sessions, resources and a 24/7 Helpline. They also provide in-person learning throughout the State of Wisconsin (<https://www.alz.org/wi>).

LEGAL DOCUMENTS

Advance Directives

Advance Directives describe, in writing, treatments you want or don't want. It tells others what to do with your care if you get injured and can't express your wishes. You can complete an advance directive if you are 18 or older and of sound mind. The Wisconsin Department of Health Services (DHS) has advance directive forms online here (<https://www.dhs.wisconsin.gov/forms/advdirectives/adformspoa.htm>). These forms are meant for you to complete without needing help from an attorney. However, you may have a situation or concern where you do want to seek legal advice from an attorney.

The forms available from the DHS include: Declaration to Physicians (Wisconsin Living Will), Power of Attorney for Health Care, Power of Attorney for Finance and Property, and Authorization for Final Disposition. These forms (or similar forms) are available from an attorney, doctor, or hospital.

Legal Decision-Making in Wisconsin

Wisconsin starts from the assumption that all adults are competent to make their own decisions, including decisions that family, friends, or community might not agree with or approve of. But if an individual is unable to make or communicate their wishes, someone else must have legal authority to make decisions to see to that individual's welfare. And Wisconsin is not a "next of kin" or "family consent" state, which means that in most circumstances, if an adult is unable to make their own decisions, spouses and relatives don't automatically have the right to make decisions for them.

The Guardianship Support Center at the Greater Wisconsin Agency on Aging Resources (GWAAR) has an excellent document that explains the following legal documents/terms: Power of Attorney for Finances, Power of Attorney for Health Care, Guardianship, Authority of Agent vs Authority of Guardian and other Advance Directives/Alternatives such as a Living Will and DNR. That document can be found here on the Guardianship Support Center website (<https://gwaar.org/guardianship-resources>).

Talking about future medical, financial and personal decisions may be difficult for families. The National Institute on Aging has an excellent worksheet you can use as a guide to start the conversation. The guide can be found here (<https://www.nia.nih.gov/sites/default/files/2023-08/what-matters-making-mdical-decisions-worksheet.pdf>). When talking about medical decisions, it might be helpful to think about what matters most when making these decisions.

NEED TO TALK?

Caregiver Support Groups

Caregiving can be incredibly isolating. Connecting with other caregivers going through similar challenges can feel like a weight has been lifted. Sometimes, all it takes is someone saying, “I’m going through that too.” And that’s what caregiver support groups are for. They are safe, non-judgmental places for caregivers to gather and share feelings, frustrations, and successes in their caregiving journey.

The ADRC hosts monthly caregiver support groups. There are many other support groups available throughout Sauk County, including specific groups such as Veteran’s, Mental Health, Parkinson’s and Dementia-Specific groups. The support group listing is found on the ADRC website under Caregiver Resources (<https://www.co.sauk.wi.us/adrc/support-groups>) or simply call the ADRC and request a listing.

In addition to in-person support groups, there are lots of options for virtual support groups throughout Wisconsin and nationwide. Wisconsin Caregiver has an excellent listing of virtual support groups and educational events to join (<https://wisconsincaregiver.org/virtual-events-for-caregivers>).

One-on-One Assistance

Sometimes you may need more support than support groups can give. Counseling allows caregivers one-on-one time to share feelings and get support. Sauk County Human Services has a Counseling Services Resource List on their website (<https://www.co.sauk.wi.us/humanservices/mental-health-and-recovery-services>).

Options Counseling

Information and Assistance is a professional service provided by Aging and Disability Resource Centers. Aging and Disability Specialists provide the general public unbiased information and referrals about services, resources and programs. This information can be obtained by emailing, calling, stopping into the ADRC office and/or through a home visit. Specialists give unbiased information so families can make the best decision for their specific situation. Call the ADRC to inquire.

ADRC CAREGIVER RESOURCES

In addition to the resources listed already in this resource guide, the Sauk County ADRC has a variety of programs available for caregivers. For information about the programs below, call the ADRC (608)355-3289.

Dementia Care Specialist

ADRC Dementia Care Specialist, Kurt Goeckermann assists families with accessing local resources, working with challenging behaviors, and planning for future care needs. Kurt is available to meet with families to discuss strategies to best meet the needs of loved ones living with dementia.

Powerful Tools for Caregivers

Powerful Tools for Caregivers is a 6-week evidence-based workshop designed with caregiver wellness in mind. It helps caregivers reduce stress and improve emotional well-being, manage time, master decision-making, communicate effectively, and much more.

Lending Library

Caregivers can borrow items on our lending library for 6 months (and longer if no one is requesting that particular item). Some of the items up for grabs are Echo (Alexa) devices, reminisce cards and DVDs, Joy for All comfort pets (no, not real!), wireless door alarms, picture memory phones, and books!

Trualta

Trualta is a free online learning portal that helps caregivers manage care at home with a library of lessons on various topics, solving day-to-day needs. Caregivers can read or print articles, watch videos, listen to lessons or practice skills with Trualta's library. Register for Trualta here (<https://wisconsincaregiver.trualta.com/>).

Well Connected

Well Connected for family caregivers is our bi-monthly caregiver newsletter which contains virtual and in-person learning opportunities, an Ask Kurt section for caregivers to submit questions, and helpful articles for the caregiving journey.

Memory Café's

A Memory Café is a gathering for caregivers and loved ones living with dementia to socialize, participate in activities, have snacks, reminisce, and have fun. The ADRC hosts a monthly Memory Café at the Fusch Community Center (2090 Ridgeview Dr, Reedsburg, WI 53959) on the 2nd Friday of each month. Kurt Goeckermann, Sauk County Dementia Care Specialist facilitates the group.

<https://www.co.sauk.wi.us/adrc>

OTHER ADRC RESOURCES

Information & Assistant Specialists (I&A)

- "Front-line" workers - receive initial calls and refer to EBS/DBS/DCS if necessary
- Provide Long Term Care assistance, initial home-delivered meal assessments, and much more
- Available for Options Counseling to learn about services available in Sauk County

Disability Benefit Specialists (DBS)

- Serve people age 18 to 59 with physical, developmental disabilities, mental illness, and substance use disorder
- Help determine benefits/program eligibility (i.e. Medicaid, SSDI, Foodshare)

Elder Benefit Specialists (EBS)

- Serve people age 60 and older
- Assist with Medicare including Part D, Medicaid, Prescription Drug Options, SSI

Transportation

- Volunteer drivers provide medical transportation to folks 60 and older and adults with disabilities
- Fun-Day & Shopping Bus trips provide socialization to local attractions /grocery stores
- Taxi tickets sold at half price the face value

Nutrition

- Provide Meals on Wheels to home-bound individuals 60 and older
- Dining sites in Sauk County serve meals and provide socialization

Prevention

- Powerful Tools for Caregivers: 6-week evidence-based workshop designed to help caregivers learn to take care of themselves while caring for a loved one
- Stepping On: 7 week evidence-based workshop designed to reduce falls by 31%

Tele-Assure

- Daily, friendly phone call from our ADRC staff to ensure well-being

Volunteer

- Volunteer Drivers, Meals on Wheels Drivers, In-Site Volunteers, Staff Support

AddLIFE Newsletter

- The AddLIFE Newsletter is a free quarterly magazine provided by the ADRC. The newsletter provides information about all of our programs including helpful articles, upcoming events, and more! Both digital and paper copies are available.

<https://www.co.sauk.wi.us/adrc>