

Time to Breathe

*Finding the Right
Respite and
How to Fund it*

Presented by Kayla Olson
Dementia Care Specialist & Caregiver Coordinator



Objectives

- Stress gauge
- Defining 'respite'
- Considerations
- Funding Aids



Disclaimer

* The Aging and Disability Resource Centers do not endorse or recommend specific facilities, agencies, or programs.



My Stress Thermometer

*STRESS: Feeling tense, nervous, anxious, restless, or unable to sleep because your mind is troubled all the time.**

Please mark your current stress level on the thermometer:

5 Extremely stressed
4 Very stressed
3 Moderately stressed
2 A little stressed
1 Not stressed at all

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©S. Boston | *Reference: Eio A-L, Leppänen A, Jahkola A, Scand J Work Environ Health 2003;29(6):444-451.

Respite is...

- Any service that "provides short-term relief for primary caregivers, giving them time to rest, travel, or spend time with other family and friends."
 - Could last a few hours, a few days, or even several weeks at a time.
 - Respite care can take place in an individual's home, in a health care facility, or at an adult day care center.

What is Respite Care? / National Institute on Aging, www.nia.nih.gov/health/caregiving/what-respite-care. Accessed 12 Apr. 2024.

Respite could also be...

- Transportation assistance
- Home chore or outdoor chore assistance
- Adaptive equipment and technology
- Expenses related to keeping caregivers socially engaged with others

(GWAAR)

Benefits

- Relieves stress
- Enhances the health and wellbeing of the caregiver
- Enhances the joy of caregiving
- Increases the quality of care you are able to provide your loved one

Common Barriers

- High Costs
- Lack of access to providers
- Lack of transportation
- Feelings of guilt or anxiety

Recognizing Signs of Caregiver Burnout

- Frequently on the verge of tears or crying
- Feeling helpless or hopeless
- Overreacting to minor nuisances
- Feeling constantly exhausted
- Losing interest in or having decreased productivity form work
- Withdrawing from social contacts
- Increasing use of alcohol or stimulants
- Change in eating or sleeping patterns
- Inability to relax
- Scattered thinking
- Feeling increasingly resentful
- Being short-tempered with care recipient frequently
- Increasing thoughts of death

Caregiving in Wisconsin

Alzheimer's and Caregiving in Wisconsin (source: Alzheimer's Association)
Wisconsin Alzheimer's Facts and Figures 2024

# of Caregivers	205,000
Total Hours of Unpaid Care	297,000,000
Total Value of Unpaid Care	\$5,528,000,000

2025 Alzheimer's Disease Facts and Figures Special Report.
www.alz.org/getmedia/61814819-3d36-48ea-8719-674034635c1a/alzheimers-facts-and-figures.pdf. Accessed 15 Oct.

Caregiving in the US 2025

- ≈ 1 in 4 American adults (24%) are family caregivers
- 59 million caregivers care for adults age 18+
- 4 million care for children under age 18 with an illness or disability
- Nearly half of the care recipients are 75+
- Most, facing multiple chronic health conditions
- 27% of caregivers reported their care recipient has Alzheimer's, dementia or another memory-related impairment.

AARP & National Alliance for Caregiving, "Caregiving in the US 2025," AARP, AARP, 26 Sept. 2025.
<https://www.aarp.org/en/topics/health/family-caregiving/caregiving-in-the-us-2025/>.

Determining what will make the biggest impact

Ask yourself
...

What two situations or responsibilities are the most stressful for you?

How could these situations be eliminated, reduced or made less stressful?

If you could remove one responsibility from your daily or weekly routine to make life easier, what would that be?

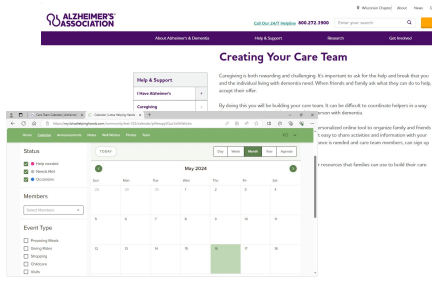
Recipes for Self-Care

- Write out a plan, correspondent with the amount of free time you have
 - i.e. 15 minutes of free time – an 8 min guided meditation
 - 1 hour of free time – time in the garage or the garden
 - 3 hours of free time – lunch with a friend or a pedicure
- Explore options for Support
 - Support Groups (in-person, virtual, telephonic, or online events)
 - Local and National Organizations



Care Coordination Tools

- [Lotsa Helping Hands](#)
- [Caring Bridge](#)
- [Caring Village](#)
- [CareNav@](#)
- [TLC](#)



Coordinating Caregiving Responsibilities

Worksheet: Coordinating Caregiving Responsibilities

Caregiving comes with many responsibilities, from helping with housework to driving an older person to doctor's appointments. It can be helpful to divide up the caregiving duties among family and friends. You can use this checklist to help you coordinate. It is arranged by type of task, such as "health and medical care." Add other activities as needed and note who is taking care of each one in the "Caregiver" column.

Type of task	Related activities	Caregiver
Household needs	Do laundry and other housework	
	Prepare meals, with awareness of any special diets or dietary restrictions	
	Shop for food and other necessities	
	Assist with home maintenance,	



Develop a Menu of Activities

- Care INFO Sheet
- Caregiver's info and emergency contact info
 - Secondary contact if caregiver is not reachable
- Care recipient's preferred hospital system, physician, medical conditions, allergies, etc.
- Care recipient's:
 - Likes
 - Dislikes
 - Routines/Rituals
 - Previous Role(s)
 - Conversation Starters
 - Hobbies
 - Interests
 - Repository of activities (and materials) that meet individual's needs, abilities, and interests
 - Potential Triggers and Calming or De-escalation Techniques

Informal/Familial Support Options:

- Family
- Friends
- Neighbors
- Faith Community
- Students
- Other caregiving/care receiving dyads
- Co-workers or previous co-workers

Formal Support Services:

- Adult Day Programming
- Supportive Homecare
 - Private caregivers vs. Agency
- Housekeeping Assistance
 - Companies or independent contractors
 - Senior center volunteer programs
- Facility, Overnight Respite Stay
- Other:**
 - Home Health
 - Palliative Care or Hospice Services

Adult Day

- Usually open during business hours
- May be a stand alone company or be located in senior centers, nursing facilities, churches or synagogues, hospitals, or schools
- The staff provide
 - an array of social activities to help individual's structure their day
 - serve meals and snacks
 - Some may monitor or help administer medications, encourage participation in physical or occupational therapy exercises or even have the ala carte option of offering bathing/shower assistance
- Some facilities may have the resources to arrange transportation to/from the center



Supportive Homecare

- Services are provided by an aide who can be hired privately, or through an agency.
- Services may be provided on a long-term or short-term basis, and may be for the purpose of providing respite to the primary caregiver.
- **Supportive home care staff can assist with:**
 - Personal care: bathing, dressing, toileting, grooming, mobility, eating
 - Household care: cooking, cleaning, laundry, grocery shopping
 - Health related care: medication reminders, doctor appointments, therapy exercises as prescribed
 - Emotional care: companionship, meaningful activities, conversation
- NOT covered by Medicare, payment sources typically include private pay, long-term care insurance, Medicaid long-term care programs, grants, Veterans' services or programs



Supportive Homecare – Private

- Make a Schedule & Write a Job Description
- Finding a Private Caregiver
 - [Wisconsin Caregiver Registry](#) | [Find a Respite Provider | RCADW](#)
 - Check with other community resources such as a church, Senior Center, SAIL, or word of mouth
 - Post on [Care.com](#) | <https://www.caregivers.com/>
 - Check with Universities and Colleges
 - Students in a health-related field**
 - Make sure you're using a reputable source when using online platforms to search
 - At a cost, could consider hiring an employment agency with a staffing service
- Interviewing and Screening
 - [Public Access - DOJ Background Checks](#)
- Negotiating Rate of Pay
- Contract/Agreement – Considerations: <https://www.caregiver.org/personal-care-agreements>
- Provide Training
- Provide Ongoing Supervision & Feedback



Supportive Homecare – Agency

- Ask about their protocols:
 - Background checks, drug screenings, credential requirements
 - References
 - Call-Out procedures (advance notice, replacement, etc.)
- Consider and inquire about the amount of training and specifically dementia training they offer their staff
- Consider care recipient needs
 - Transportation?
 - Evenings or Weekends?
 - Overnight care?
- Payer sources accepted
- Minimum Service Hour Requirements



Home Chores / Outdoor Assistance

- Ask friends, family, or neighbors for recommendations.
 - If feasible, involve family members or friends in the cleaning process to share the responsibility and reduce the need for frequent professional services.
 - Check with local community centers, senior centers, or religious organizations. They might have information on affordable cleaning assistance or volunteers.
 - Check online reviews to get an idea of the services, quality, and reliability.
- For Cleaning:**
- Decide if you'd prefer independent house cleaners or cleaning companies:
 - **Independent house cleaners** are usually found through "word of mouth."
 - A background check is recommended.
 - **Cleaning Companies** screen their workers beforehand and are often bonded and insured.
 - **For Outdoor Maintenance**
 - Snow removal AND lawn care? Fall clean-up?



Facility, Overnight Stays

- Some facilities will offer short-term respite stays (≈ at least 5 days, more often 2 weeks-14 days)
 - Usually private-pay or grant-funded, usually not covered by Medicare or insurance
- Call your local [ADRC](#), Area Agency on Aging, State Unit on Aging (SUAs) to inquire
 - Call 844-WIS-ADRC (844-947-2372) for help finding your local ADRC or Tribal ADRS



**When looking for grants or resources,
consider...**



U.S. Department of Veterans Affairs
(must be enrolled in VA health care)

- **Program of General Caregiver Support Services (PGCSSL)**
 - Includes caregiver training & support, respite care, coaching and peer support mentoring.
 - Under this program, caregivers do not need to be a relative or live with the Veteran
 - General caregivers provide personal care services to a Veteran **enrolled in VA healthcare** who:
 - » Needs assistance with one or more activities of daily living or
 - » Needs supervision or protection based on symptoms or residuals of neurological impairment or other impairment or injury



U.S. Department of Veterans Affairs
(must be enrolled in VA health care)

- **Program of Comprehensive Assistance for Family Caregivers (PCAFCC)**
 - Offers enhanced clinical support and services for caregivers of veterans who:
 - » Incurred a serious injury/illness in the line of duty
 - *"For purposes of PCAFCC, serious injury means any service-connected disability that: (1) is rated at 70 percent or more by VA; or (2) is combined with any other service-connected disability or disabilities, and a combined rating of 70 percent or more is assigned by VA."*
 - » Need in-person personal care services of a min. of 6 continuous months based on any of the following:
 - An inability to perform an activity of daily living;
 - A need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury; or
 - A need for regular or extensive instruction or supervision without which the ability of the Veteran to function in daily life would be seriously impaired.



Alzheimer's Family Caregiver Support Program (AFCSP)

- This program was created to enhance the lives of informal and family caregivers while helping people with dementia remain living in the community as long as possible.

Eligibility Criteria:

1. Documented diagnosis of Alzheimer's disease or other dementia from a healthcare professional.
2. The person with dementia resides in the community or in a residential facility.
(if in facility, funds may not be used for room & board, and are prioritized for persons living in the home with fewer resources.)



National Family Caregiver Support Program (NFCSP)

- This program offers respite, supplemental services, information, support, and other resources to family caregivers.

Eligibility Criteria

- Primary caregiver aged 18 and over who provides unpaid care to a frail person age 60 or older, or to a person of any age who has Alzheimer's disease or related dementia.
- Grandparents or relatives aged 55 and older who are the primary caregivers for a child under age 18 who live with them or older relatives, including parents, age 55 and older providing care to adults ages 18-59 with severe disabilities who live with them.

Ineligible if:

- The care recipient is on a Long Term Care Medicaid Program.
- Currently enrolled in AFCSP (can receive both grants in the same calendar year, just not simultaneously).



Respite Care Association of Wisconsin (RCAW)

1. Caregiver Respite Grant Program (CRGP)

- Provides financial support for family caregivers for up to five days of respite care within 30 days of approval. The grant helps you pay for one-on-one personal care from the respite care provider of your choice for your loved one living with disabilities or special needs.

Eligibility Criteria:

- Applied for a Long-term Care Waiver or other program and not expecting to receive services or approval within thirty (30) days of the application
- Has been denied Long-Term Care Waiver support(s) or other programs that provide respite services
- Has been approved for Term Care Waiver support(s) or other programs that provide respite services and has exhausted funds from said programs
- Has applied and is receiving other supports, and the applicant needs flexibility for services not covered by current funding supports
- Has not applied for a Long-Term Care Waiver support(s) because they are ineligible for other



RCAW Continued...

2. Supplemental Respite Grant Program (SRGP)

- Can provide up to \$250 for supplemental services such as:
 - Housekeeping, meal prep, laundry, lawncare, snow removal, transportation, technology

Eligibility Criteria:

- Has applied for a Long-term Care Waiver or other programs and not expecting to receive services or approval within thirty (30) days of the application
- Has been denied Long-Term Care Waiver support(s) or other programs that provide respite services
- Has been approved for Term Care Waiver support(s) or other programs that provide respite services and has exhausted funds from said programs
- Has applied and is receiving other supports, and the applicant needs flexibility for services not covered by current funding supports.
- Has not applied for a Long-Term Care Waiver support(s) because they are ineligible for other supports



RCAW Continued...

3. Healthy Meals, Healthy Minds (HMHM) Grant Program for Family Caregivers

- Can provide up to \$250 for services promoting mental health, wellness, and nutritious meals through meal kits.

Eligibility Criteria:

- Has applied for a Long-term Care Waiver or other programs and not expecting to receive services or approval within thirty (30) days of the application
- Has been denied Long-Term Care Waiver support(s) or other programs that provide respite services
- Has been approved for Term Care Waiver support(s) or other programs that provide respite services and has exhausted funds from said programs
- Has applied and is receiving other supports, and the applicant needs flexibility for services not covered by current funding supports.
- Has not applied for a Long-Term Care Waiver support(s) because they are ineligible for other supports



Other potential grant or in-home assistance opportunities

(not an all-inclusive list)

- [The Alzheimer's Association](#)
 - [Dementia Caregiver Respite Grant](#) (Arkansas)
- [The Association for Frontotemporal Degeneration/Comstock Grants](#)
 - The maximum annual grant is \$500/family. *Recipients may use the funds on respite care, mental health support, or self-care (yoga, exercise class) that best meets their needs.*
- [American Parkinson's Disease Association](#)
 - Funding for community & individual financial assistance has been exhausted for the year (as of 4.15.24) but they are looking to locate additional funds.
- [Calrasu All Things Alzheimer's](#)
- [Willyby for Charity](#)
- [National Multiple Sclerosis Society](#)
 - Financial Assistance
- [Medicare/DeanCare Gold member](#)
 - Has partnered with Papa Pals to offer 5 hours per month of assistance with household tasks, technology, or transportation.
- [Road Scholar](#)
 - [Caregiver Grants | Road Scholar](#)

