

# Caregiver Support Programs: What You Need to Know

**Bryn Ceman, M.S.**

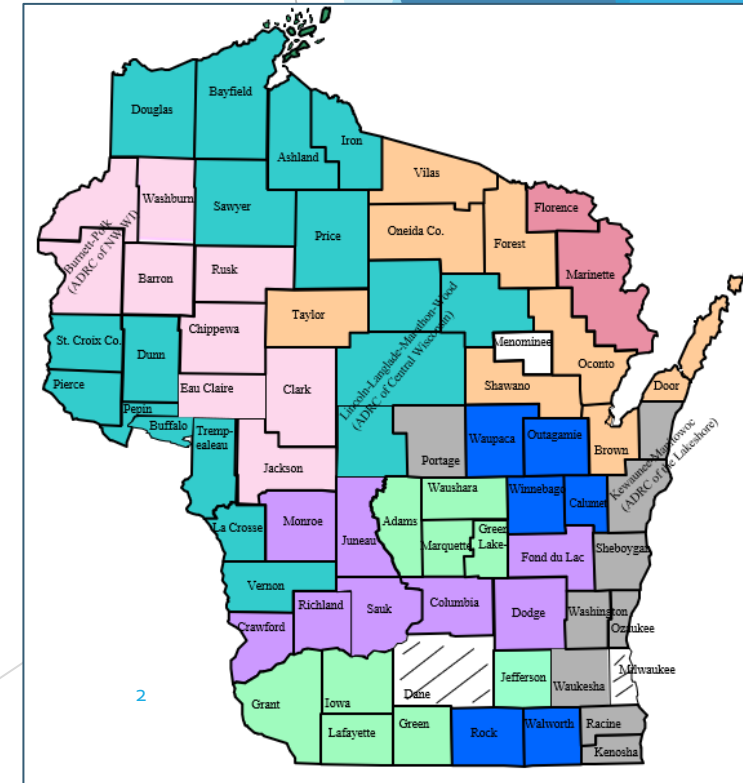
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September 7<sup>th</sup>, 2022 1 pm – 2 pm  
Respite Care Association of Wisconsin  
Webinar Wednesday

# Introduction



- ▶ Greater Wisconsin Agency on Aging Resources – GWAAR
- ▶ Provide Technical Assistance across state
  - 70 county and 11 tribal Aging Units
- ▶ Wisconsin Legislature created the Alzheimer's and Family Caregiver Support Program (AFCSP) in 1985
- ▶ Older Americans Act of 1965
  - 2000 National Family Caregiver Support Program (NFCSP)



# 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
- ▶ Those who will need a caregiver



— Rosalyn Carter, American Writer, Activist, and served as the First Lady of the United State from 1977 to 1981



# Caregiving Statistics

- ▶ AARP Wisconsin estimates that the state's 580,000 family caregivers provide the equivalent of about \$7 billion in free services annually.
- ▶ Of those Wisconsin Caregiver, 60% of family caregivers had full- or part-time jobs.
- ▶ Nationally, upwards of 75% of all caregivers are female. [Institute on Aging. (2016). Read How IOA Views Aging in America.]

Sources: <https://states.aarp.org/wisconsin/wisconsin-family-caregiving-legislation-federal-tax-credit> and [AARP - WI Caregivers Provide \\$7 Billion in Unpaid Care \(aarp.org\)](#) and

## The State of Family Caregiving in Wisconsin and Nationally

### PROFILE OF CAREGIVERS IN AMERICA

- 82% care for 1 adult
- 15% care for 2 adults
- 3% care for 3+ adults

On average, caregivers help with 4.2 Instrumental Activities of Daily Living

- Caregivers by Race:
- 16.9% White
  - 19.7% Asian American
  - 20.3% African American
  - 21% Hispanic

\$28+ billion in lost productivity for full/part-time employed caregivers

49% felt they had no choice in taking on this role

85% provide care to a relative

28% of caregivers have a child or grandchild living with them

8.4 million provide care to an adult with an emotional or mental health issue

17.9 billion hours of unpaid care for people with Alzheimer's & related dementias

600,000-700,000 families have an adult with I/DD living with aging family members with no future planning



### Definitions

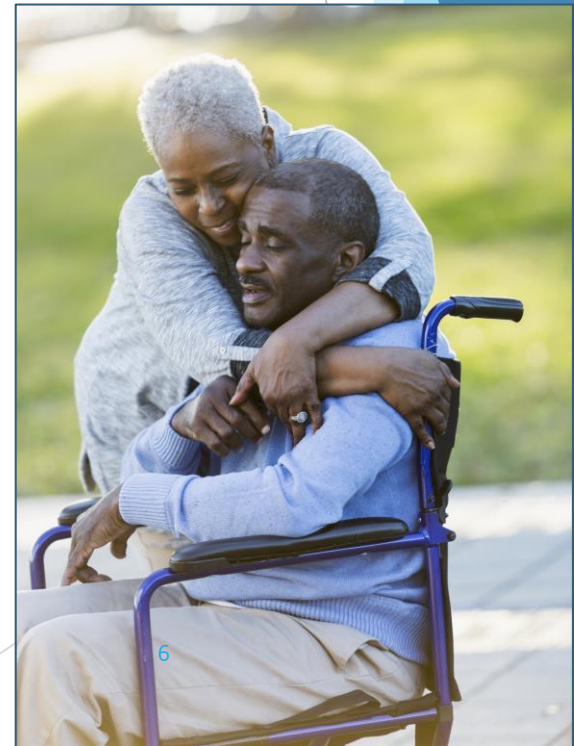
A **caregiver** - sometimes called an **informal caregiver** - is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.

**Formal caregivers/Direct Care Workers** are paid care providers providing care in one's home or in a care setting (day care, residential facility, long-term care facility). For the purposes of the present fact sheet, displayed statistics generally refer to caregivers of adults.

# Overcoming Barriers

## ▶ People tend to think...

- I am just his spouse (daughter, son, parent, grandparent, etc.). This is what I am expected to do
- I don't live *with* her
- I don't do *that much* for them
- But I *want* to do this
- She took care of me, now it's my turn
- This is just what family does



# Are YOU a Caregiver?

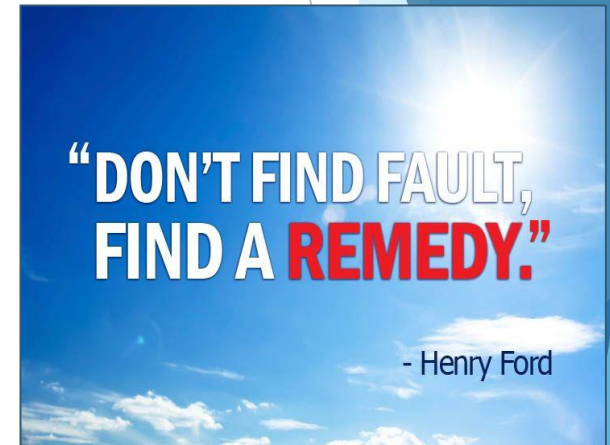
▶ **Do you do any of the following:**

- Take meals to ensure nutritious food is available
- Help with cleaning and laundry
- Assist with weekly grocery shopping
- Arrange medical appointments and provide transportation
- Feel the need to check up on the person to be sure they are okay
- Receive frequent phone calls with requests for help
- Provide on-going care to someone such as help bathing, dressing, grooming or provide supervision due to dementia

*If you answer YES to any of the questions, you are a caregiver.*

# Overcoming Barriers

- ▶ Governor's Task Force on Caregiving and some highlights:
  - Aging and Disability Resource Center (ADRC) Reinvestment, specifically Caregiver Support
  - Family Medical Leave Act Amendments
  - The Wisconsin Credit for Caring Act
  - The Care Act Direct Care Workforce Proposals
  - State-Wide Direct Support Professional Training
  - Home Care Provider Registry Pilot
- ▶ Other states such as New Jersey, Washington, Arizona, Nevada, Illinois, New Mexico, and Hawaii are offering National solutions too!





# Wisconsin's Alzheimer's Family & Caregiver Support Program (AFCSP)

- ▶ Wisconsin Legislature created the Alzheimer's and Family Caregiver Support Program (AFCSP) in 1985
- ▶ Program was created to enhance the lives of informal and family caregivers while helping people with dementia remain living in the community for as long as possible.
- ▶ Funds are available in each county for qualified individuals to provide temporary caregiver relief through respite and purchase goods & services needed that are needed to help care for someone with irreversible dementia.
- ▶ Counties do an excellent job of trying to make the dollars stretch. Though, some counties may have a waitlist for services.

# Wisconsin's Alzheimer's Family & Caregiver Support Program (AFCSP) Continued

## ▶ Who is Eligible?

1. There is a diagnosis of Alzheimer's disease or other irreversible dementia.
2. The person with dementia resides in a community or home setting.
3. The person with dementia and spouse have a gross annual income of \$48,000 or less.
  - Costs related to dementia care may be deducted when calculating gross income.

# Wisconsin's Alzheimer's Family & Caregiver Support Program (AFCSP) Continued

## ▶ What can the Program Provide?

### Typical goods & services include:

- Respite care or home care services (personal care assistance, meal prep, medication assistance & monitoring, homemaker services, yard work, and snow removal, etc.)
- Emergency response systems
- Transportation expenses
- Incontinence supplies
- Home safety modifications
- Home-delivered meals
- Specialized clothing
- Activities and hobby supplies
- Legal expenses related to guardianship
- Caregiver counseling services
- Caregiver education classes
- Individualized services as approved

# National Family Caregiver Support Program (NFCSP)

- ▶ Older Americans Act of 1965
  - 2000 National Family Caregiver Support Program (NFCSP)
- ▶ NFCSP offers respite, information, support, and other resources to family caregivers.
- ▶ Caregiver support services are available to all families caring for a person 60 or older or someone with dementia. Grandparents and older relatives caring for a minor child or children or an adult with a disability may also qualify for the program.

# National Family Caregiver Support Program (NFCSP) Continued

## ▶ Who is Eligible?

- Caregiver who is 18 years or older where the Care Recipient is 60 or older and the Care Recipient is “Frail”
- Caregiver who is 18 years or older where the Care Recipient is between age 19 & 59 with Early Onset Dementia
- Caregiver is 55 years or older where the Care Recipient is a relative under age 19
- Caregiver is 55 years or older where the Care Recipient is a relative between age 19 & 59 and is disabled.
- There are no fees or income requirements to enroll in NFCSP.

# National Family Caregiver Support Program (NFCSP) Continued

## ► What can the program provide?

- Limited short-term respite care provided in or out of the home
- Other respite: yard work, snow shoveling or light /heavy housework
- Personal care such as dressing, bathing or toileting
- Companionship and general supervision for safety purposes
- Services and items that assist the caregiver in providing care such as: transportation & assisted transportation, assistive devices, minor home modifications (\$5,000 annual limit), supplies, and safety equipment

# AFCSP and NFCSP Enrollment

## ▶ How do I apply?

- Contact your County or Tribal Aging Office or Aging & Disability Resource Center (ADRC) to apply. Specifically inquire about AFCSP and/or NFCSP.
- <https://wisconsinicaregiver.org/local-resources>
- Enter your county or zip code or click on the map for a phone number, email, and address for your county Aging Unit and/or ADRC.
- Link to [ADRC Brochure](#) in multiple languages.

### The information you need for the life you want.

Sometimes situations change so quickly, you don't know where to begin. Or you may be so overwhelmed with opinions, you aren't sure whose to trust.

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#### Start with the Aging and Disability Resource Centers

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Our welcoming locations offer unbiased answers to all questions related to aging or living with a disability. We don't sell anything. We aren't affiliated with a company or product. Instead, we help Wisconsin residents stay independent by connecting them with the resources they need.

Your best life starts with the right information. Find it here, at your Aging and Disability Resource Center.

### Get the answers and resources you need.

Visit or contact your local ADRC today.

*Accommodations, materials in alternate formats, and after-hour appointments are available upon request. Hearing loops are available on site; please call to arrange for interpreters or captionists.*

**FindMyADRC.org**



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## Independent. Like you.

Unbiased information to help you live the life you want.



# Tips to be a Healthy Caregiver

- ▶ Find someone to talk to – support group, professional, friend
- ▶ Maintain healthy diet and exercise regularly
- ▶ Stay involved in hobbies & activities – caregiving will end one day
- ▶ Take regular breaks – daily, weekly
- ▶ Accept help - people want to help so let them!
  - Keep list of things you could use help with
- ▶ Take advantage of community resources





# Additional Resources

- ▶ Aging Well Class and virtual on Wisconsin Family Caregiver [Support Groups](#)
- ▶ Wisconsin Department of Health Services (DHS): [Dementia Care Specialist Program](#)
  - Online webinars available from 2021
  - FREE program and resources
  - Dementia Care Specialists are available across the state & work for the Aging and Disability Resource Center (ADRC). [Find an ADRC](#)
- ▶ In just six weeks, [Powerful Tools for Caregivers](#) can help you identify and manage the physical, emotional and financial challenges that family caregiving can present and connects you with other caregivers who are facing some of the same feelings and problems you may be facing.
- ▶ Follow @WisconsinFamily Caregiver to see posts and information about advocacy, age friendly, in-person events, articles, podcasts and more.
- ▶ Johns Hopkins: [Called to Care](#)

# Trualta Free eLearning: Trualta



LEARN HOW TO  
**KEEP YOUR LOVED  
ONE HAPPY AND  
HEALTHY AT HOME**

INCLUDING BRAIN HEALTH, SAFETY &  
INJURY PREVENTION AND PERSONAL CARE.

- Improve confidence and **reduce stress** by learning care skills
- **Helpful tips** available in print, audio, video, eLearning and more
- Login to the website on any computer, tablet or smartphone - **no app required!**



*And the fact that you  
can do a module in five  
minutes is great!*

- **JERRY, 65,**  
CARING FOR HIS WIFE WITH  
ALZHEIMER'S

Coming Soon!

Register for Early Access

# Additional Resources

## ▶ CAREGIVING APPS

- [Agefully](#)– UW-Madison School of Nursing has created an evidence-based guidance, support and planning tool for adult children caring for aging parents. The app will help caregivers anticipate need, explore options and prepare for the future.
- [Alzheimer's Caregiver Buddy](#) - Focuses on providing support for the caregiver by giving in-the-moment tips and tricks in areas of daily routine, communication, behaviors, activities of daily living. It also provides live help 24 hours a day by clicking and calling the Alzheimer's Association 24-hour helpline.
- [Care Angel](#) - Free app that offers "artificially intelligent" caregiver calls to older adults that track their condition, includes care circle contacts must be offered by insurer, employer, senior living or other.
- [CareZone](#) – Helps manage overall caregiving duties, including coordination of friends and family, health care record keeping and scheduling with a shareable calendar.

# Additional Resources

## ▶ CAREGIVING APPS

- [CaringBridge](#) - Allows you to create a site for yourself or the person you're caring for and invite family and friends to join. It's intended for a larger group of family and friends to stay informed, to coordinate caregiving & post notes of support.
- [First Aid by American Red Cross](#) - Get instant access to information on handling the most common first aid emergencies.
- [Symple](#) – Gives you a way to track the ebb and flow of your symptoms over time such as health concerns, mood, steps and sleep. Also includes an interactive journal.
- [Pacifica](#) – Daily tools for stress and anxiety alongside a supportive community. Based on Cognitive Behavioral Therapy & Meditation. (Mindfulness app)

## ▶ Online Resource:

- [Lotsa Helping Hands](#) – Creates a connected community with family and friends where you can post news and coordinate assistance for your loved one through a shared calendar.

Sources: AARP – *Apps to Help Caregivers Stay Organized*: <http://www.aarp.org/home-family/caregiving/info-2016/caregivers-scheduling-apps-ag.html> and Mashable - *10 essential apps all caregivers should know*: <http://mashable.com/2016/09/25/apps-for-caregiving-caregivers/#R671UseeAsqo>

# Rewards of Caregiving

- ▶ A chance to “give back” to someone important in your life
- ▶ Spend more time with your loved one
- ▶ Learn more about your family history
- ▶ Opportunity to learn new skills
- ▶ Recognize your own support system
- ▶ Become more compassionate and loving
- ▶ Boost to plan your own future



# Rewards of Caregiving

- ▶ Become an advocate!
- ▶ The Greater WI Agency on Aging Resources, Inc. (GWAAR) has been awarded grant funding to implement a “Changing the Care Conversation” grant project in Wisconsin.
- ▶ The grant helps us build the grassroots power of family caregivers. to launch a national learning and action-oriented initiative to improve support for family caregivers.
- ▶ The goal is to advance state and federal policy solutions that strengthen supports for family caregivers. The project runs from 4/01/22 – 4/01/23.
- ▶ If you know a current or former family caregiver who might want to become a part of this exciting new project and is willing to participate in online training and support, please have individuals contact Bryn Ceman at [bryn.ceman@gwaar.org](mailto:bryn.ceman@gwaar.org).



Thank you!

## Find an Aging & Disability Resource Center:

[Find an Aging and Disability Resource Center | Wisconsin Department of Health Services](#)

**Email:** [Bryn.Ceman@gwaar.org](mailto:Bryn.Ceman@gwaar.org)

**Phone:** 608-228-8096