



Strengthening the Backbone: Advancing Support for Wisconsin's 580,000 Family Caregivers

Dementia Diagnostic Clinic Network
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LEARNING OBJECTIONS

1. Recognize the critical role family caregivers play in care delivery.
2. Understand the physical and emotional toll caregiving takes.
3. Identify clinical strategies, resources, and policy solutions that strengthen caregiver and patient outcomes.



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- Provide 490+ million hours of unpaid care annually
- Value to the healthcare system: \$7 billion per year
- 1 in 3 also care for children—compounding stress
- Majority are women, often middle-aged or older

580,000+ family caregivers in Wisconsin



WHO ARE WISCONSIN'S FAMILY CAREGIVERS?



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WHAT CAREGIVERS ARE DOING AT HOME

- Administering meds, injections, wound care
- Monitoring symptoms and triaging care
- Managing appointments, ADLs, and mobility
- Handling complex discharge instructions
- Quote: "62% perform skilled tasks. Only 14% receive training." (AARP)*
- Supporting behavioral and cognitive health



*Reinhard, S. C., Levine, C., & Samis, S. (2012). "Home Alone: Family Caregivers Providing Complex Chronic Care." AARP Public Policy Institute and United Hospital Fund



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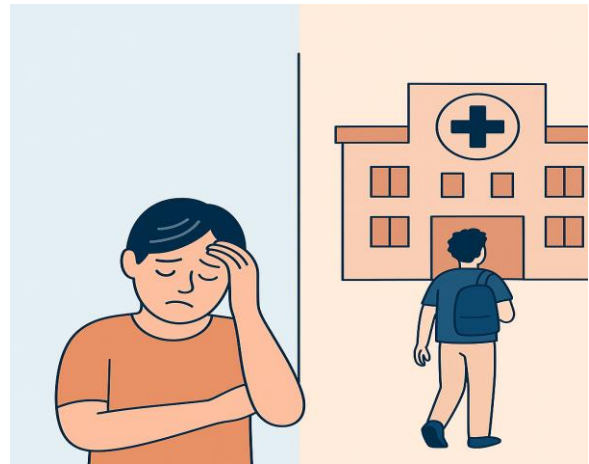
IMPACT ON CAREGIVER HEALTH & PATIENT OUTCOMES

40–70% of caregivers experience clinical depression

Chronic stress = higher risk of hypertension, diabetes, insomnia

Caregivers more likely to skip their own care appointments

Caregiver burnout = patient risk: med errors, missed follow-ups



Zarit, S. H. (2006). *Assessment of Family Caregivers: A Research Perspective*. | National Alliance for Caregiving & AARP. (2020). *Caregiving in the U.S.* [Schulz, R., & Sherwood, P. R. (2008). *Physical and Mental Health Effects of Family Caregiving*. *Am J Nurs*, 108(9 Suppl), 23–27. | AARP Public Policy Institute. (2017). *Breaking Stereotypes: Meeting the Needs of Family Caregivers of Adults with Mental Health Conditions*. | The Joint Commission. (2018). *Quick Safety Issue 50: Supporting Caregivers*. Schulz, R., & Eden, J. (Eds.). (2016). *Families Caring for an Aging America*.

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WHO EXPERIENCES CAREGIVING?

- In short, everyone!
- Rural caregivers often travel long distances and have limited access.
- LGBTQ+ caregivers may encounter systemic barriers and cultural stigma that complicate their caregiving experience.
- Tribal caregivers may rely on traditional, community-based models of care that are often overlooked in mainstream systems.

**As Mrs. Carter famously said,
There are only four kinds of people in the world: those who have been caregivers, those who will be caregivers and those who will need caregivers.**



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How Clinical Teams Can Strengthen Outcomes

- Ask: “Who’s helping at home?”
- Ask about challenges.
- Include caregivers in discharge planning
- Refer to: ADRCs, Trualta, RCAW
- Document caregiver role in EHR
- Watch for burnout signs



Clinical Workflow with Caregiver Integration



*AARP and National Alliance for Caregiving's "Caregiving in the U.S." reports (2020 version).

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Why Family Caregivers Matter in Clinical Settings

- Caregivers essential for:
 - Post-discharge coordination
 - Medication reconciliation
 - Chronic condition management
- Reduce readmissions and ER visits
- 50% say providers don't ask about their needs*



Clinical Workflow with Caregiver Integration



*AARP AND NATIONAL ALLIANCE FOR CAREGIVING'S "CAREGIVING IN THE U.S." REPORTS (2020 VERSION).

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Wisconsin's Family Caregiver Support Programs (NFCSP)

National Family Caregiver Support Programs (NFCSP)



Caregiver support services are available to all families caring for a person aged 60 or older or someone with dementia. Grandparents and older relatives caring for minor children or an adult with a disability may also qualify for the program. Services can include respite, chore services, and more.

<https://gwaar.org/api/cms/viewFile/id/2007225>

Wisconsin 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.

<https://gwaar.org/api/cms/viewFile/id/2005362>

WISCONSIN CAREGIVER PROGRAMS YOU CAN LEVERAGE

WisconsinCaregiver.Org



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WISCONSIN CAREGIVER PROGRAMS YOU CAN LEVERAGE

- [Respite Care Association of Wisconsin Respite Services \(RCAW\)](#):
 - [Caregiver Respite and Supplemental Respite Grant Programs](#)
- [Trualta](#) (Free)
- [ADRCs](#) (statewide access)
 - [Dementia Care Specialist Program](#)



 <https://wisconsincaregiver.trualta.com/login>

 **RCAW**
Respite Care Association of Wisconsin
<https://respitecarewi.org/>

 **ADRC**
Aging and Disability Resource Center
<https://www.dhs.wisconsin.gov/adrc/index.htm>

 Wisconsin Family and Caregiver Support Alliance
<https://wisconsincaregiver.org/>

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ADVANCING CAREGIVER SUPPORT: KEY UPDATES

- **SB 152/AB 176:** Remove AFCSP income cap; bipartisan support (30+ legislators).
- **Caregiver ID:** Embed into assessments & EHRs.
- **Training Resources:**
 - [CMS YouTube – Caregiver Training](#)
 - [MLN – Billing & Coding Training](#)
 - [MedBridge – CPT Codes Overview](#)
- **Association Links:** [AAFP](#) | [ASHA](#) | [AOTA](#) | [APTA](#)



QUESTIONS???

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