

Caregiver Burden and Support

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Disclosure

- No conflicts to disclose
- As a Geriatrician, I am going to focus on caregivers for older adults for this talk, but with the acknowledgment that caregivers have similar challenges and needs, no matter who they are helping

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Objectives

- Define "caregiver burden" or "caregiver stress" and describe the impact of caregiver burden on older adult patients, their families, and caregivers themselves.
- Describe possible strategies for screening for and identifying caregiver burden across a variety of clinical settings.
- Describe initial steps that physicians / providers can take when they identify caregiver burden to reduce the risks of patient and caregiver harm and to improve overall caregiving outcomes.

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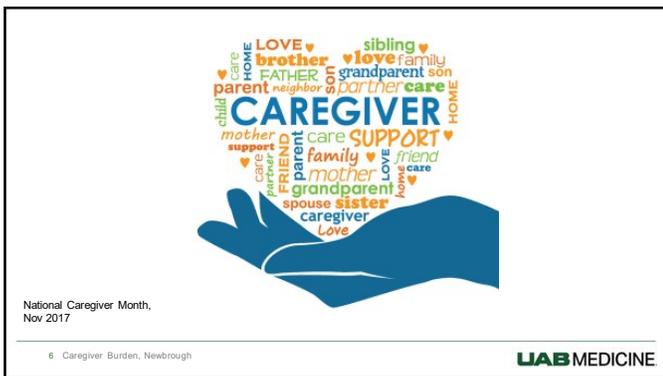
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CAREGIVING

2015-2018 Behavioral Risk Factor Surveillance System (BRFSS) Data
Data source: U.S. Census, Family Issues, and the Bureau of Economic Analysis

1 in 5 adults are caregivers

CAREGIVING provides regular care or assistance to a FRIEND or FAMILY member with a chronic condition or disability

WHY ARE CAREGIVERS?

- 58% are women
- 19% are 65 years old or older
- 37% are caring for a parent or parent-in-law
- 9% are providing care to someone with dementia

HOW DO CAREGIVERS RELIEF?

- Nearly 80% report financial strain
- Over 50% assist with personal care

FUTURE CAREGIVERS

- 1 in 6 non-caregivers expect to become caregivers within 5 years

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Centers for Disease Control: Sept 2024

- > 53 million unpaid caregivers in US
- Equivalent of nearly \$470 billion a year in free care.
- Number of caregivers increased from 43.5 million in 2015 to about 53 million in 2020.
- By 2035, estimated 78 million people in the US will be 65 years or older.
- More than 2/3 of US population will likely need help with tasks at some point in their lifetime.

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CDC: Health impacts of Caregiving (2021)

- Nearly 1 in 5 caregivers report fair or poor health.
- Caregivers often neglect their own health needs, increasing their risk of having multiple chronic conditions
- Nearly 2 in 5 caregivers have at least two chronic diseases of their own

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CDC: Financial strains of caregiving (2021 study)

- Many employed caregivers miss work to give care, losing wages.
- Nearly 2 in 20 employed caregivers report having to stop work entirely.
- 4 in 10 have had to reduce their hours to provide care for a loved one.
- Almost 80% of caregivers reported paying out-of-pocket for routine expenses for care recipients
- The average out of pocket cost for caregivers was \$7,200
- Cost rose to nearly \$9,000 per year for caregivers of someone with dementia

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Carer / Caregiver Burden

"burden" is defined as something difficult or unpleasant that you have to deal with or worry about, or a duty or responsibility that is hard to bear.

"Carer / Caregiver burden": the physical, emotional, and financial strain experienced by individuals who care for someone with a chronic illness, disability, or who is elderly. It can manifest as stress, anxiety, physical health problems, financial strain, and impaired relationships.

Cambridge English Dictionary

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Caregiver Burden Can Be Hard to Talk About

- Impossible to talk about in front of the person they are caring for
- Depending on relationships / arrangements, may harbor a tremendous amount of guilt when acknowledging burden and its impacts
- For many caregiving situations, help seems unattainable, especially to the caregiver
- Low levels of health literacy common barrier, increase worry for caregiver
- Systems and processes not supportive enough:
 - E.g., how should we document that caregiver is burdened, and where?
 - Consider those common caregiving scenarios where the patient is cognitively intact, but physically disabled. Modern electronic record note sharing with patients can make it harder to document and keep team informed.

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Alzheimer's Assoc. 10 symptoms of Caregiver Stress

- **Denial**-about disease and effect on person who has it
- **Anger**-at the person with AD or frustration over deficits
- **Social withdrawal**- from friends and activities that bring pleasure
- **Anxiety**- about the future, even just tomorrow
- **Depression**- "I just don't care anymore"
- **Exhaustion**- hard to do even basic daily tasks
- **Sleeplessness**- caused by never-ending list of concerns, including wandering
- **Irritability**- may lead to moodiness and triggered responses (negative)
- **Lack of concentration**- difficult to perform familiar tasks
- **Health problems**- mental and physical toll

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When Caregiver Burden Becomes Burnout

- High risk for compassion fatigue → poor behaviors toward the patient, including abuse and neglect and other forms of mistreatment
- Increased risks for hospitalization and long-term care placement
- Increased risk of self-harm for caregivers
- Devastating for patient, caregivers, and others who care about them
- Burnout is not completely predictable, and the risks not always foreseeable
- As providers and our team members, we are really caring for patients, caregivers, and often families.

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CMS Attestation Measure

Domain 4: Social Vulnerability: This domain seeks to ensure that hospitals recognize the importance of social vulnerability screening of older adults and have systems in place to ensure that social issues are identified and addressed as part of the care plan.

A. Older adults are screened for geriatric specific social vulnerability including social isolation, economic insecurity, limited access to healthcare, caregiver stress, and elder abuse to identify those who may benefit from care plan modification.

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Be aware, learn to recognize signs of caregiver burden

- Caregiver appears tired / exhausted
- Caregiver appears frustrated (or worse) with the patient
- Caregiver is not able to answer basic questions they should know (and perhaps used to be able to answer without difficulty)
- Caregiver expresses or demonstrates emotional distress
- Poor eye contact, fidgety, distracted
- Your staff / other team members express question / concern

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CBI: Physical Health Items

I'm not getting enough sleep.
My health has suffered.
Caregiving has made me physically sick.
I'm physically tired.

Scoring:
0-Never
1-Rarely
2-Sometimes
3-Quite frequently
4-Nearly Always

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CBI: Emotional Health Items

I feel embarrassed over his/her behavior.
I feel ashamed of him/her.
I resent him/her.
I feel uncomfortable when I have friends over.
I feel angry about my interactions with him/her.

Scoring:
0-Never
1-Rarely
2-Sometimes
3-Quite frequently
4-Nearly Always

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CBI: Social Relationship Items

I don't get along with other family members as well as I used to.
My caregiving efforts aren't appreciated by others in my family.
I've had problems with my marriage (or other significant relationship).
I don't get along as well as I used to with others.
I feel resentful of other relatives who could but do not help.

Scoring:
0-Never
1-Rarely
2-Sometimes
3-Quite frequently
4-Nearly Always

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CBI Scoring / Interpretation

24 items, scores 0-4.

Possible max score 96.

Scores near or above 36 indicate a greater need for respite and other services.

Responses of 3 or 4 on any item may indicate a need for assistance / intervention.

Scoring:
0-Never
1-Rarely
2-Sometimes
3-Quite frequently
4-Nearly Always

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Alzheimer's Association Caregiver Resources

- 24 / 7 Helpline:
 - 800-272-3900 to connect with live person
 - Dial 711 to connect with telecommunications relay service (TRS) for people who are deaf, hard of hearing or speech impaired
 - Interpreter services accommodate more than 200 languages
- ALZNavigator: Connects caregiver with local, problem-specific resources
- Tons of education offerings on topics like wandering, stages and behaviors, caregiving by disease stage, educational programs, caregiver health, local support groups

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• <https://www.alz.org/help-support/caregiving/stages-behaviors>



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Area Agency on Aging

The Area Agency on Aging (AAA) serving the area near Henry Ford Genesys in Grand Blanc, MI is the **Valley Area Agency on Aging (VAAA)**. The VAAA serves older adults and disabled individuals in Genesee, Lapeer, and Shiawassee counties. Headquarters located in Flint, MI. Here is their contact information:

- **Address:** 225 E 5th St #200, Flint, MI 48502, USA
- **Phone Number:** +1 810-239-7671
- **Website:** <https://valleyareaaging.org/>
- **Opening Hours:** Monday - Friday: 8 AM - 4 PM, Saturday & Sunday:

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Valley Area Agency on Aging (VAAA)

The VAAA offers a range of services to support seniors and their caregivers, including:

- **Information and Assistance:** Connect with an Options Counselor to learn about available resources.
- **Caregiver Support:** Including respite care and caregiver training/education.
- **Nutrition:** Meals (including home-delivered meals and congregate meals) and nutrition counseling.
- **Health and Wellness:** Exercise classes, pain management, and recreation programs.
- **Ombudsman Services:** Advocating for residents in long-term care facilities.
- **Medicare/Medicaid Assistance Program (MMAP):** Free health insurance counseling.
- **Senior Centers:** The Grand Blanc Senior Center, located at 12632 Pagels Drive, Grand Blanc, MI, is one of the senior centers the VAAA works with

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National Resources for Caregivers (from GRS)

Resource	Website
AARP Home and Family Caregiving Resource Ctr.	www.aarp.org/home-family/caregiving/
Alzheimer's Association online tools page	www.alz.org/care/alzheimers-dementia-online-tools.asp
American Cancer Society Caregivers & Family Page	www.cancer.org/treatment/caregivers.html
American Heart Association Support Network	www.heart.org/HEARTORG/Support/Support_UCM_001103_SubHomePage.jsp
American Psychological Association-Connecting with Caregivers	www.apa.org/pi/about/publications/caregivers/consumers/index.aspx

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National Resources for Caregivers (from GRS)

Resource	Website
CMS Nursing Home Compare tool	www.medicare.gov/nursinghomecompare/search.html
Family Caregiver Alliance	www.caregiver.org
Medline Plus	www.nlm.nih.gov/medlineplus/healthtopics.html
National Academy of Elder Law Attorneys-Find a Lawyer	https://www.naela.org/findlawyer
National Adult Day Services	www.nadsa.org

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National Resources for Caregivers (from GRS)

Resource	Website
National Alliance for Caregiving	www.caregiving.org/resources/
National Institute on Aging-Health Information	www.nia.nih.gov/health
National Institutes of Health-Health Information	Search www.nih.gov/healthinformation using key word caregiver or a specific disease or condition
PubMed Health	www.ncbi.nlm.nih.gov/pubmedhealth/
Rosalynn Carter Institute for Caregiving	www.rosalynncarter.org/caregiver_resources/

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National Resources for Caregivers (from GRS)

Resource	Website
SAGE* National Resource Center – Caregiving Resource Page	www.lgbtagingcenter.org/resources/inex.cfm?s=3

* Advocacy and services for older adults who are lesbian, gay, bisexual, or transgender

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Caregiver Reference Binder

- Personal data section
- Calendar
- All about us (including What Matters)
- Medication list
- Health care contacts
- Social care contacts

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Helping Caregivers: Provider role

- Be supportive
- Communicate effectively, give caregiver opportunity to express needs and respond.
- Express gratitude to the caregiver for their efforts
- Offer praise for their efforts when opportunity arises
- Help them set reasonable expectations for themselves, and the overall caregiving situation. E.g., not all falls are preventable.
- Know your community resources, offer / make referrals as needed
- Encourage caregivers who are burdened to seek help in their role and for themselves.

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Policy Changes Desired by Caregivers

- 49% of caregivers surveyed wanted their names to be part of the care recipient's medical record
- 41% wanted health care providers mandated to notify them of major health care decision
- 43% wanted mandated instruction on hospital discharge
- 33% wanted respite care as part of health policy

• The figures on this slide come from research conducted by the National Alliance for Caregiving (NAC) and the AARP Public Policy Institute on caregiving in the United States (www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf).

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Thank you

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