D-CAN Fall Dementia Caregivers Conference 2022

Welcome!

Fall Dementia Caregivers Conference 2022

- **Welcome!**
  - Introduction/housekeeping
  - Objectives today
  - Exhibitors
  - Agenda
  - Disclaimers
  - Audience questions

Central Minnesota DEMENTIA COMMUNITY ACTION NETWORK

Fall Dementia Caregivers Conference 2022

- **Agenda:**
  - Welcome: Pat Zook, MD
  - Keynote: Dr. Joseph Gaugler
  - Exhibitor interviews/C.G. tips: Bob Hughes
  - Break for 30 minutes
  - Panel discussion
  - Closing remarks
  - Lunch with Exhibitors

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Disclaimer

While our 2022 Dementia Fall Conference Sponsors, and general support sponsors, have provided Central Minnesota Dementia Community Action Network (DCAN) and our Dementia Resource Center Clinic (DRCC) in St. Cloud, MN with financial and in-kind support, and support our mission of "Improving ACCESS to QUALITY dementia care in our community," they are NOT endorsing or supporting any particular methodology, protocols, treatment, exhibitors/vendors, or products mentioned/featured in any of the 2022 Dementia Fall Conference content/material discussed and/or featured therein. Also, DCAN/DRCC, and the speakers featured, are NOT providing any medical advice and anyone seeking such advice should consult with their medical clinician(s) and/or specialist(s) for any individual medical advice and/or recommendations for medical treatment.

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UNDERSTANDING DEMENTIA CARE AND SUPPORTING DEMENTIA CAREGIVERS

JOSEPH E. GAUGLER, PH.D.

Robert L. Kane Endowed Chair In Long-Term Care & Aging, Professor

Director, Center for Healthy Aging and Innovation

Director, BOLD Public Health Center of Excellence in Dementia Caregiving

SCHOOL OF PUBLIC HEALTH

UNIVERSITY OF MINNESOTA

ACKNOWLEDGEMENTS

AIMS

- Summarize the effects of dementia caregiving
- Taking a step back: Why does all of this matter?
  - **Dementia caregiving as a public health priority**

THE SCOPE OF DEMENTIA CAREGIVING

- 83% of all help provide to older people in the U.S. comes from family members or other unpaid individuals
- Nearly half of all caregivers (48%) provide help to someone with ADRD
- More than 11 million dementia caregivers in U.S.
- 6 billion hours of dementia care = $271.6 billion

WHY?

- A desire to keep a family member or friend at home (65%)
- Proximity to the person with dementia (48%)
- Perceived obligation to the person with dementia (38%)
  - Sense of love and duty

WHO ARE DEMENTIA CAREGIVERS?

2/3 are women	**30% are 65+**	**60% married/long-term partnership**
Over half providing care to parent/PiL	**2/3 White, 10% Black, 8% Hispanic, 5% Asian American**	**41% have a household income of <$50,000**
2/3 live with the care recipient	**¼ are "sandwich" generation caregivers**	**57% have provided care for 4+ years**
Of those who provide >40 hours/week of care, 73% are women	**Black caregivers are 69% less likely to use respite services**	**More Black caregivers provide >40 hours of care per week (54.3% versus 38.6%) than White caregivers**

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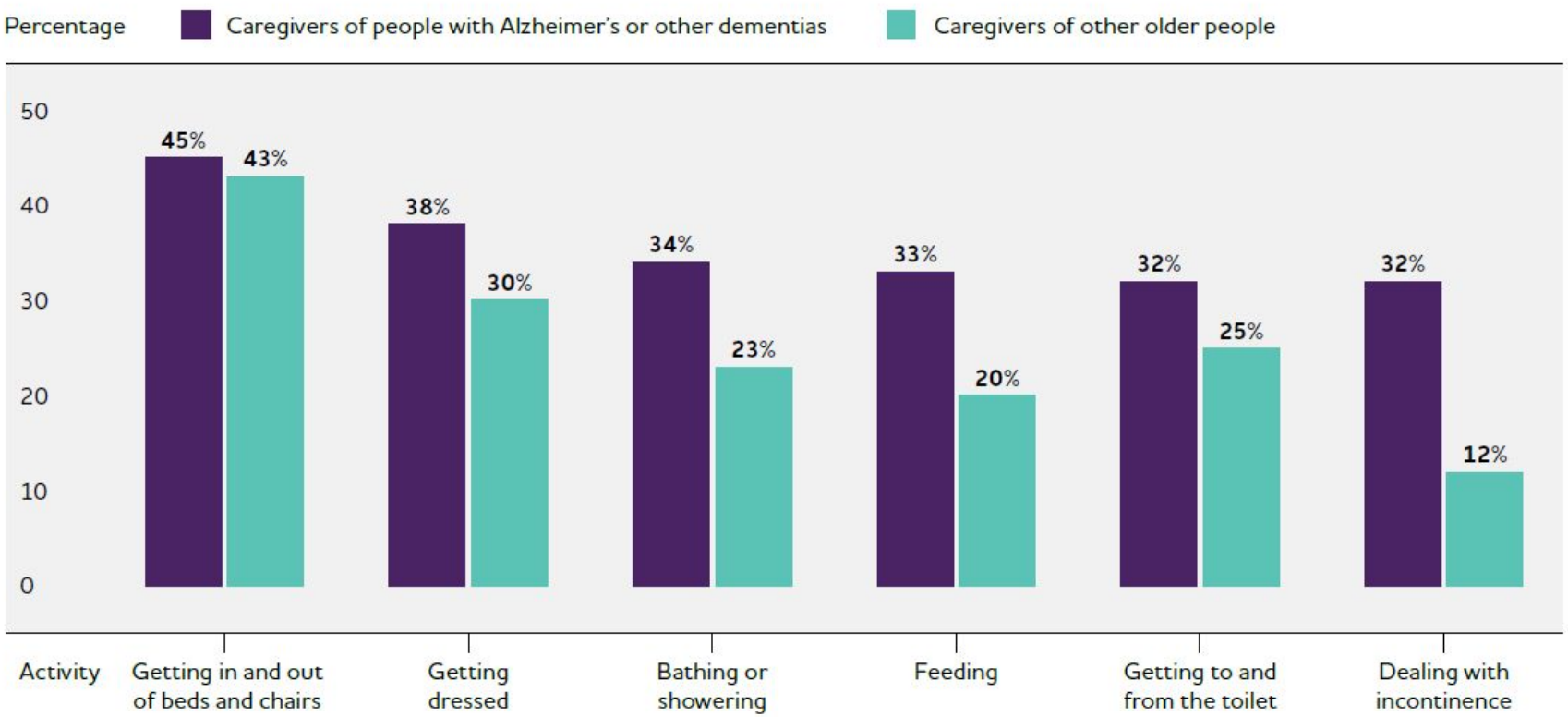
WHAT DO DEMENTIA CAREGIVERS DO?

Help the person with instrumental activities of daily living (IADLs)c
Help the person take medications correctly
Help the person adhere to treatment recommendations for dementia or other medical conditions
Assist with personal activities of daily living (ADLs)
Manage behavioral symptoms of the disease
Find and use support services
Make arrangements for paid in-home, nursing home or assisted living care
Hire and supervise others who provide care
And much more…

figure 9

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.[398]

DURATION OF CAREGIVING

- Close to six in ten of dementia family caregivers had provided care for four or more years

MINNESOTA INFORMATION

State	Number of caregivers (in thousands)	Hours of unpaid care (in millions)	Value of unpaid care (in millions)
Minnesota	171	156	3,358

WHAT ARE THE EFFECTS OF CAREGIVING?

Twice as many dementia CGs indicate emotional, financial, and physical difficulties that non-dementia CGs	Spousal dementia care is associated with a 30% increase in depressive symptoms compared with non-dementia CGs	Dementia CGs are twice as likely as non-dementai CGs to report difficulty when completing medical/nursing related tasks (22% vs. 11%)
41% of dementia caregivers provide help alone	In the year before the death of the person living with dementia 59% of caregivers felt they were “on duty” 24 hours a day	45% indicated dementia care as very rewarding

MINNESOTA INFORMATION

State	Percentage of Caregivers Reporting at Least One Chronic Condition	Percentage of Caregivers Reporting Depression	Percentage of Caregivers Reporting Frequent Poor Physical Health
Minnesota	55.3	29.9	14.4

WHAT CAN WE DO? INTERVENTIONS

table 11

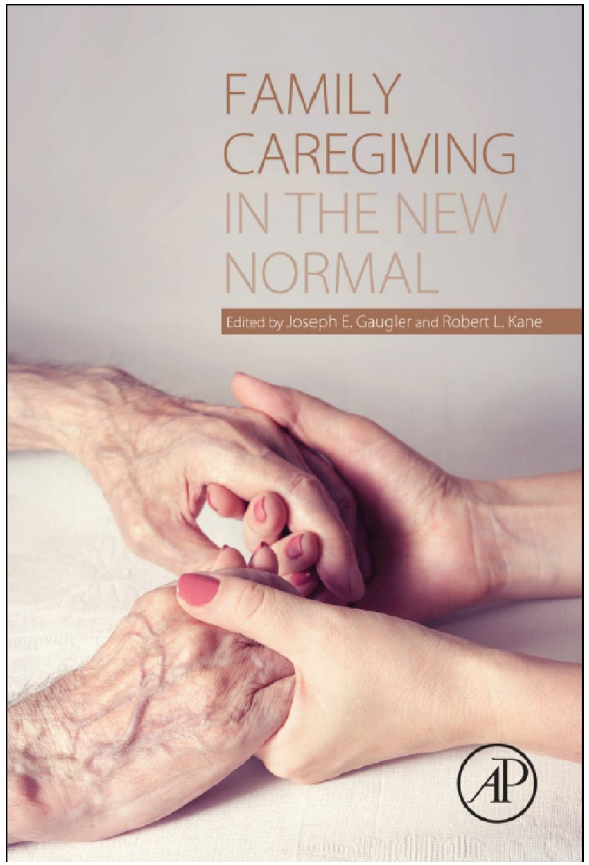
Type and Focus of Caregiver Interventions

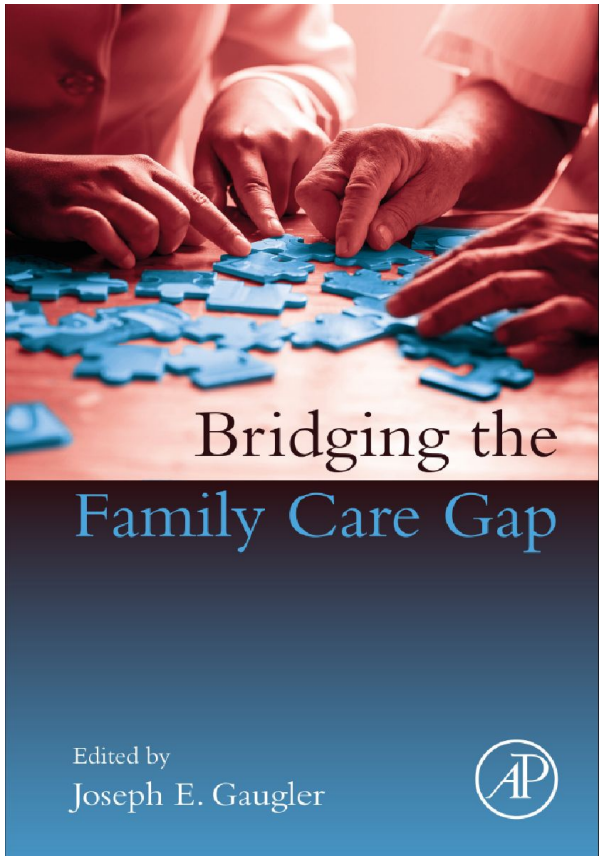
Type	Focus
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational approaches	Include structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve preexisting personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite care for a certain number of weekly hours.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of isolation.
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of intervention, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

Created from data from Pinquart et al,[449] Gaugler et al[517] and Walter and Pinquart.[529]

WHY IS DEMENTIA CAREGIVING A PUBLIC HEALTH PRIORITY?

- It affects the health of the population—including both caregivers and care recipients
- The effects may be unequally borne by some members of that population
- There are effective prevention strategies that could be employed to reduce these negative impacts.
- **Is dementia caregiving a social determinant of health?**





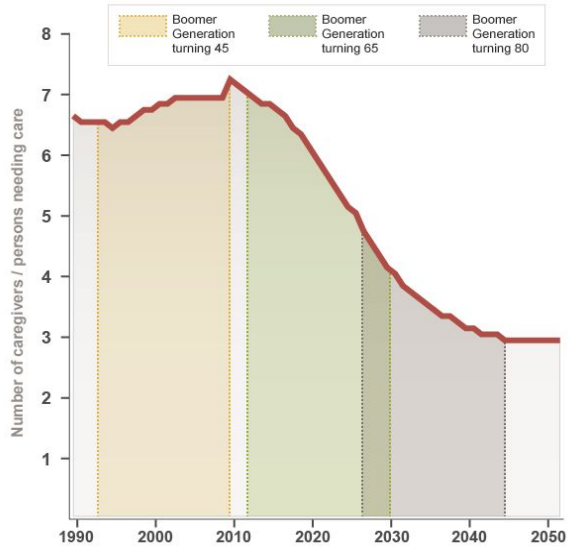
-Gaugler, J. E., & Kane, R. L. (Eds.). (2015). *Family caregiving in the new normal*. San Diego, CA: Academic Press.
-Gaugler, J. E. (Editor) (2021). *Bridging the family care gap*. San Diego, CA: Academic Press.

IS OUR RELIANCE ON FAMILY CAREGIVING SUSTAINABLE?

You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio



In **2010**, the caregiver support ratio was more than **7** potential caregivers for every person in the high-risk years of 80-plus.

In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/ppi

HOW CAN WE BRIDGE THE FAMILY CARE GAP?

- Develop a national family caregiving strategy
- Achieve “family-centered” care, or approaches that more effectively incorporate family caregivers into healthcare delivery
- Advocate for the widespread dissemination and implementation of evidence-based supports and services for family caregivers
- Develop and/or support policies and programs that have a public health impact (Plichta, 2018)

JOE'S FINAL THOUGHTS

- Breaking down siloes
  - Public health and the aging service network
  - Disabilities and the aging service network
- Integration of community-based supports and services
  - Healthcare systems
  - Health plans (i.e., Medicare Advantage)

ENGAGE WITH US!

- Center for Healthy Aging and Innovation
  - http://sph.umn.edu/chai
  - Twitter: @UMNCHAI
- BOLD Public Health Center of Excellence on Dementia Caregiving
  - http://bolddementiacaregiving.org
  - Twitter: @PHCOE_DC
  - "I Am A Caregiver" page: https://bolddementiacaregiving.org/caregiver/
- Families and LTC Projects
  - https://www.sph.umn.edu/research/projects/ltc/

CARING FOR A PEOPLE WITH MEMORY LOSS CONFERENCE

- Free annual community education conference held at the University of Minnesota
  - Held Saturday after Memorial Day
  - Joseph E. Gaugler, PhD, organizer (612-626-2485; gaug0015@umn.edu)
- Approximately 200-330 attendees
- Free food!
- Hands-on, relevant talks on issues ranging from stress reduction strategies to financial planning
- CEUs for purchase ($50 for 6-7 contact hours)
- Virtual library of presentations, resources, and other info
- See http://z.umn.edu/memorylossconference for more information
- If you are interested in being added to our email list, please email fltc@umn.edu!

QUESTIONS?

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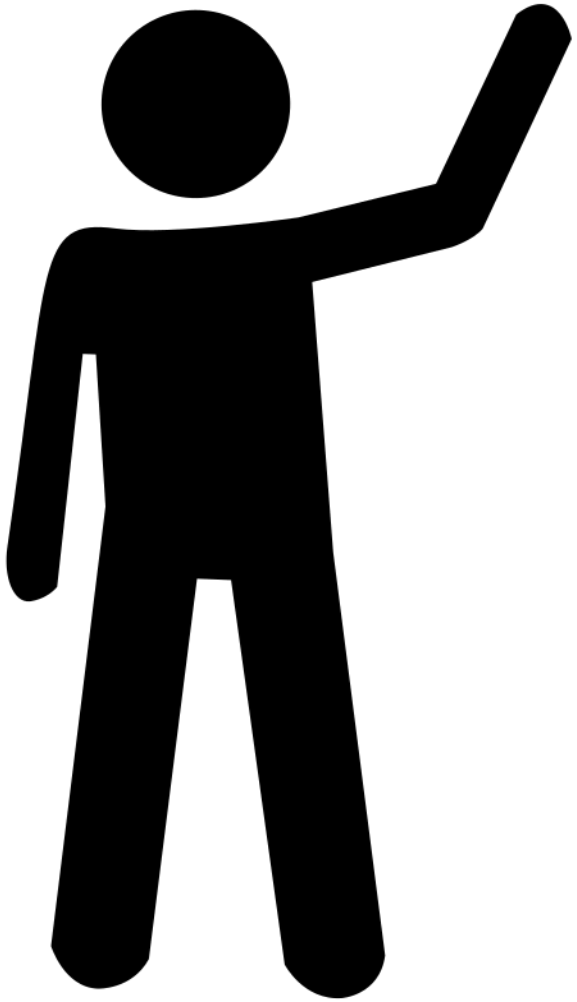

Caregiver Tip:

Stick to a daily routine. Daily routines not only benefit people living with dementia, but they also help reduce caregiver stress.

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Caregiver Tip:

Reduce Frustrations. Consider putting objects in the same place or doing the same tasks at the same time of the day.

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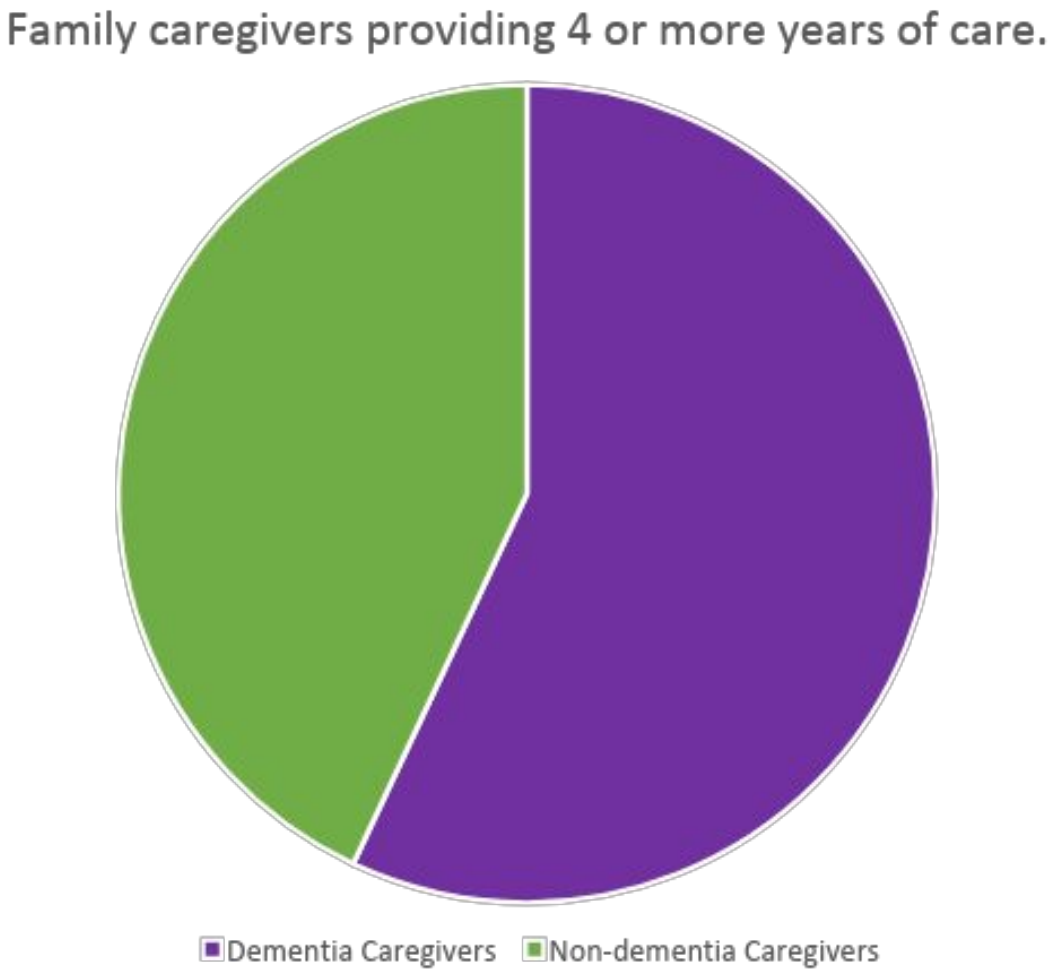
Caregiver Fact:

Over half (57%) of dementia family caregivers provide care for 4 years or more.

***www.cdc.gov**



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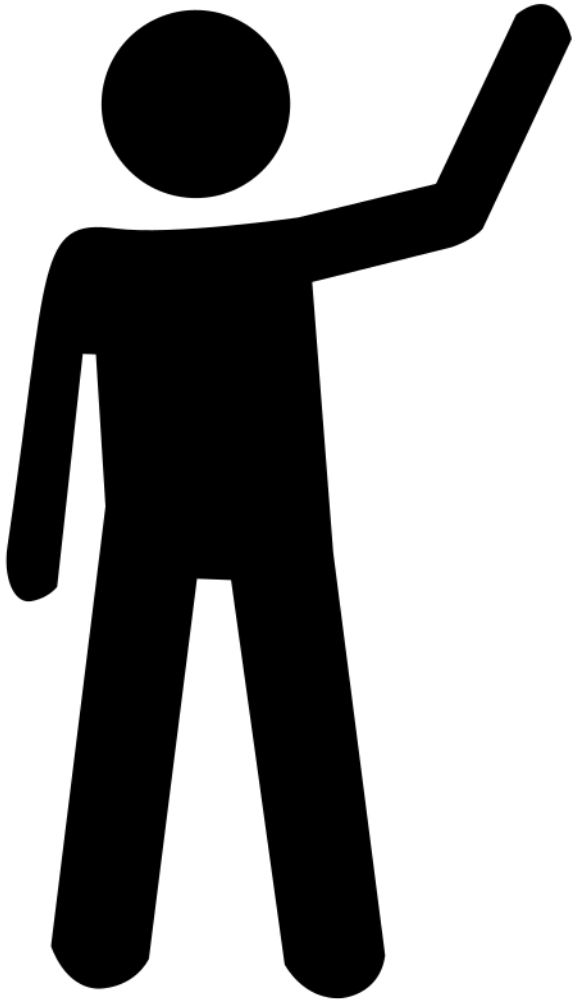

Caregiver Tip:

Be Patient and flexible. Continue to make plans for yourself and those you care for but expect them to change. Be willing to go with the flow.

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Caregiver Tip:

Stick with what is familiar. Find a schedule or routine that works and stick with it. Try to limit the number of new daily or unplanned tasks.

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Caregiver Fact:

The majority (80%) of people with Alzheimer's or other related dementias are receiving care in their homes.

*www.cdc.gov

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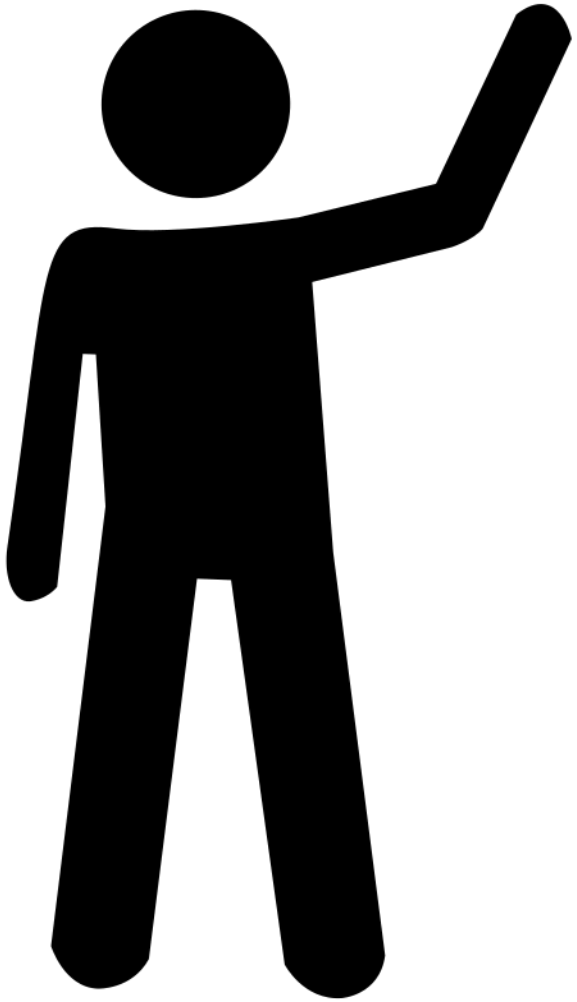

Caregiver Tip:

Never argue.
Dementia is not a choice; no amount of arguing will change the course of their memory.
Even if you have a clear point, it is best to never argue.

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Caregiver Tip:

Stay social.
As a caregiver it is essential that YOU remain socially engaged with your community, friends and family.

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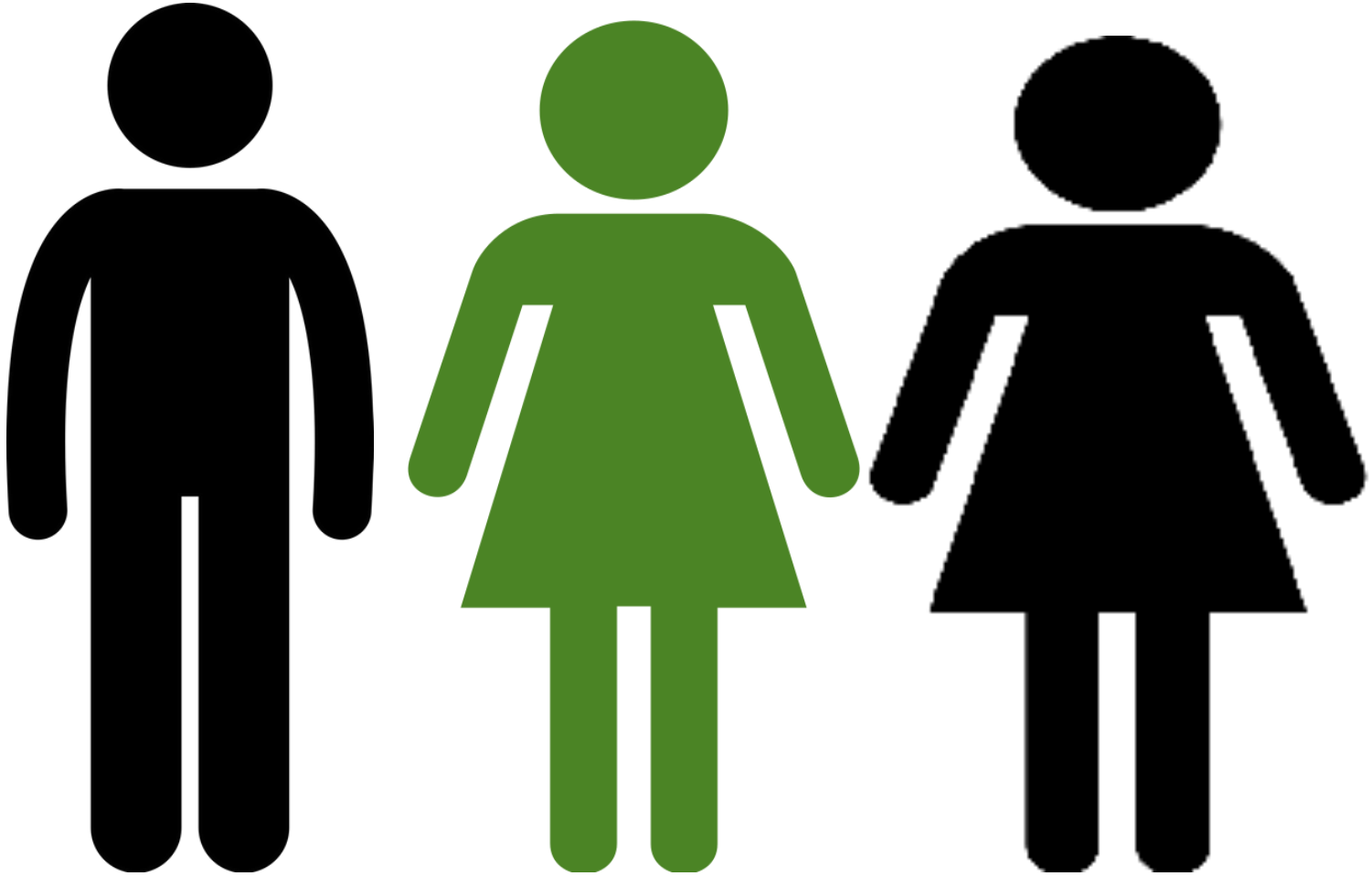
Caregiver Fact:

Approximately two-thirds of dementia caregivers are women.

*www.cdc.gov



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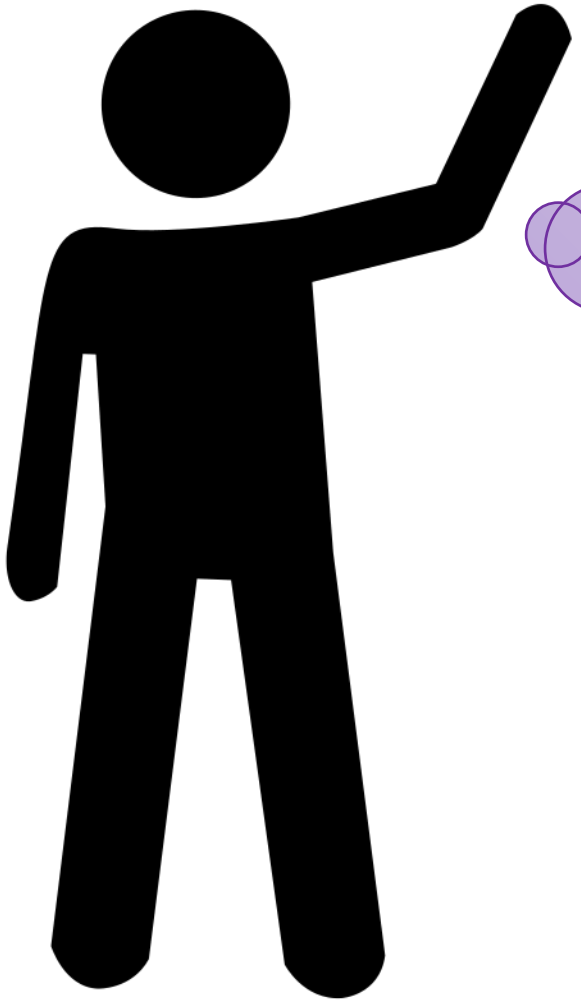

Caregiver Tip:

Avoid using “why” questions.
Instead, consider asking questions that start with who, what, where or how.
These foster more positive conversations.

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Caregiver Tip:

Accept help.
As often as you can, accept help with caregiving. Being a caregiver is not a journey we are meant to take alone.

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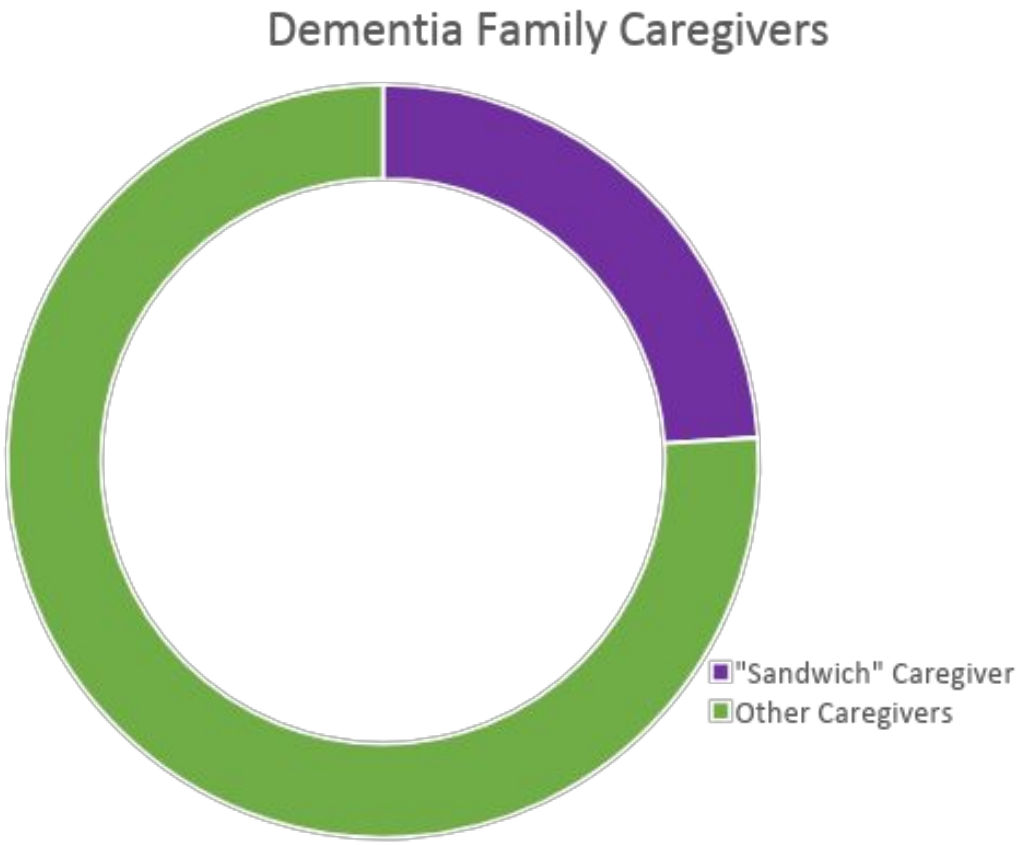
Caregiver Fact:



Approximately one-quarter of dementia family caregivers are "sandwich generation" caregivers, meaning that they care not only for an aging parent, but also for children under 18.

*www.cdc.gov

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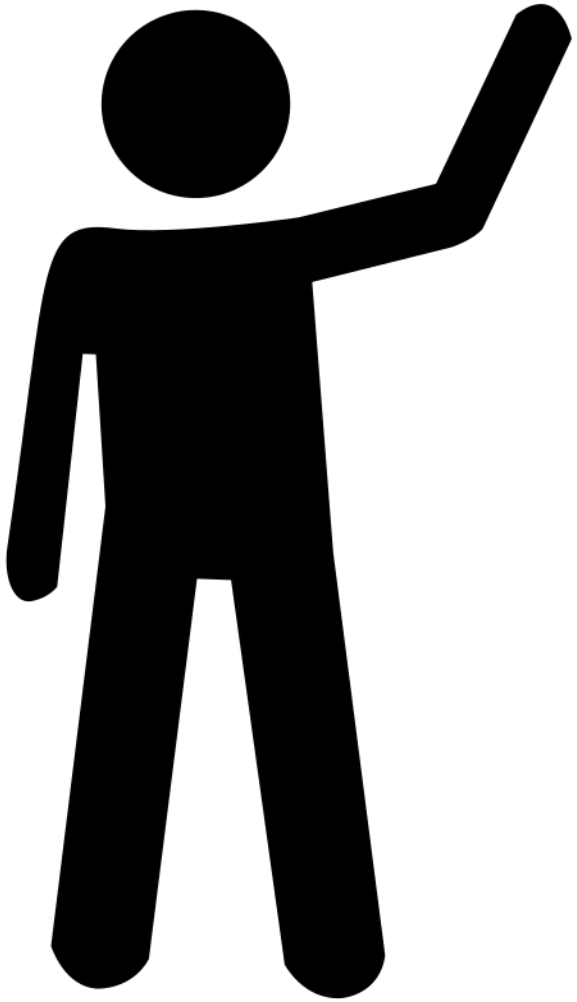

Caregiver Tip:

Make time for yourself. Caregiving can be a stressful job. Be sure to care for yourself too. Make and keep YOUR doctor and self-care appointments.

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Caregiver Tip:

Continue to learn about your loved one's dementia. Find local support to help you understand what a journey with dementia may look like.

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Caregiver Fact:

Nearly **one in three** caregivers (34%) is age 65 or older.

*www.cdc.gov

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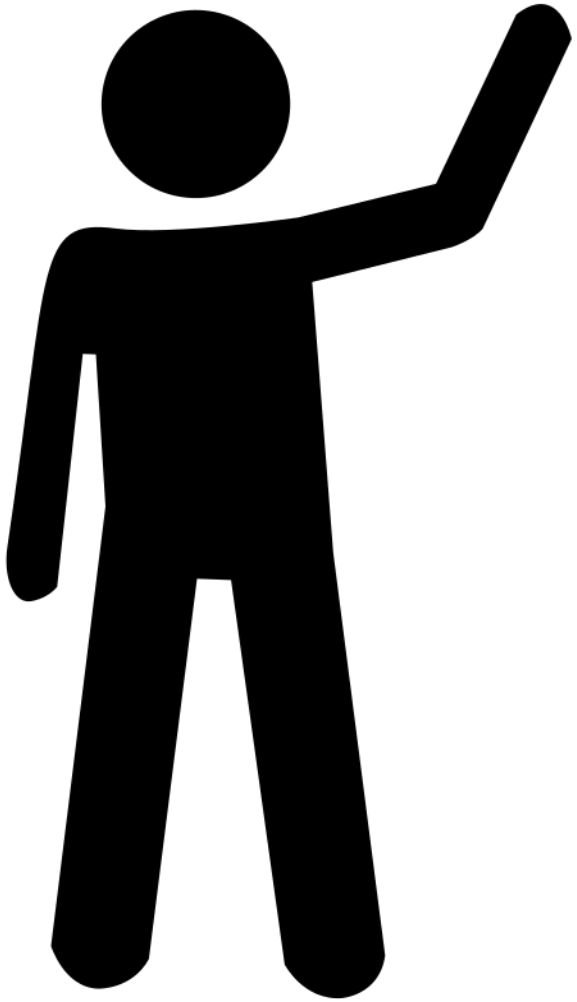

Caregiver Tip:

Set realistic expectations. Understand and accept the current limitations of those you care for.

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Caregiver Tip:

There is a reason behind every "behavior". Behaviors may be a result of an unmet need. Could they be cold? Hungry? Thirsty? Need to use the facilities?

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WE TURNED MIDSOTA CENTER PURPLE.

Visit DRCC in Suite 103

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Panel Discussion: *Caregiver Health, Support & Resources*

Dr. Pat Zook

Dr. Kim Tjaden

Jodi Danielson

Lori Vrolson

Paula Woischke

Melody Vachal

Rachael Wenner

Bob Hughes

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- **Thank You's:**
  - Dr. Joseph E. Gaugler, PhD
  - Sponsors
  - Grantors: Minnesota Board on Aging, United Way, MMA
  - D-CAN Board, Staff, Volunteers
  - Donors, collaborators, panelists
  - SPNN and Saint Paul Neighborhood Network
  - St. Cloud State University IT department, Atwood staff, catering department.
  - Bob Hughes of KNSI morning radio
  - TJ (Thomas) Stang – piano
  - Kirk Lamb- Photographer
  - Saint Cloud Crush Interact, RSVP Volunteers

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- **Contact D-CAN/ DRCC:**

- Physical Address:3701 12th Street North, Suite 103 St. Cloud, Minnesota
- Website: DCAN-MN.org
- Phone: 320-640-6726
- pzookmd@dcan-mn.org
- Like and follow us on Facebook.
- dcan-mn.org

Please take a moment to fill out our Fall Dementia Caregivers Conference survey. They are on the pink paper in your folders. Turn in to a Volunteer or at the exit door. Thank you!

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DEMENTIA SUMMIT 05.04.23

Learn the latest in dementia research, innovation, and medical care

SPEAKERS • Q&A • LUNCH

Registration opening this spring.
Follow D-CAN for updates.