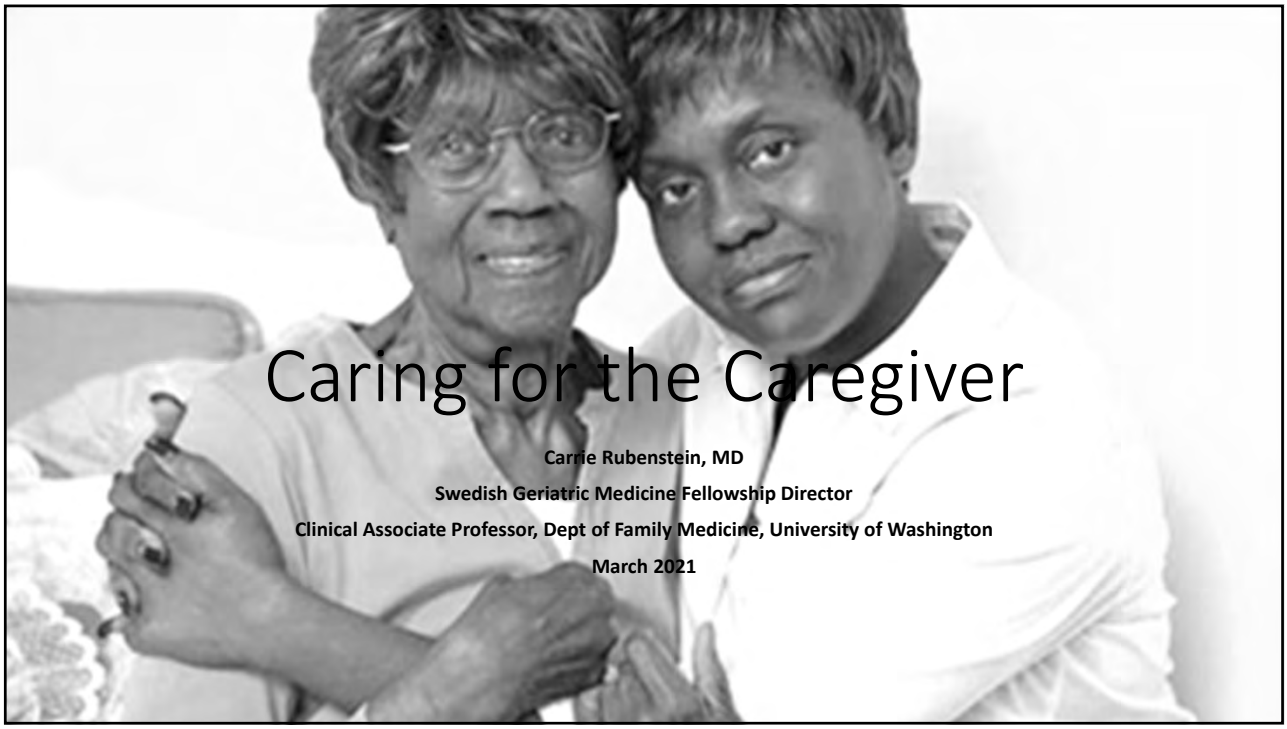


Caring for the Caregiver

Carrie Rubenstein, MD

Swedish Geriatric Medicine Fellowship Director

Clinical Associate Professor, Dept of Family Medicine, University of Washington

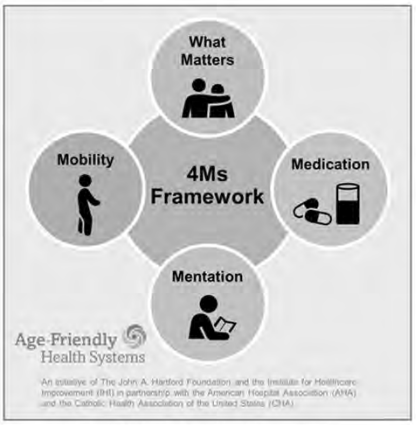
March 2021

Who am I?

- Family physician and geriatrician
- Early career practicing family medicine at a community health center
- Clinician-educator
- 6 years at Swedish, family medicine faculty and geriatrics fellowship director
- Interest in interprofessional education and geriatrics workforce

SWEDISH

Age-Friendly * 4Ms



What Matters
Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication
If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation
Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility
Ensure that older adults move safely every day in order to maintain function and do What Matters.

Caregiving is Personal to Me

Guiding Questions

- Who are the dementia caregivers?
- What challenges do they face?
- How do we support dementia caregivers through their caregiving journey?

Guiding Questions

- Who are the dementia caregivers?
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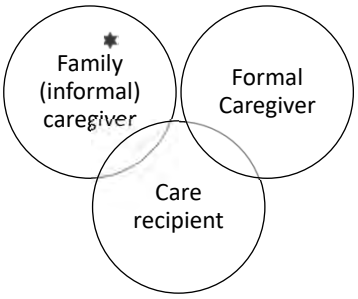
Who are the Caregivers?

- Definitions, terminology and language (it matters!)
- Review the numbers

Terminology

What is a Caregiver?



https://www.caregiver.org/
The mission of Family Caregiver Alliance (FCA)

Dementia Terminology

Dementia words matter: Guidelines on language about dementia (The Dementia Engagement and Empowerment Project [DEEP], 2014). Available at: **http://dementiavoices.org.uk/2014/10/dementia-words-matter/**

Language Matters

Instead of These Words and Cues:	Try:
"Tidal wave," "tsunami," and similarly catastrophic terms for the growing population of older adults	Talking affirmatively about changing demographics: "As Americans live longer and healthier lives…"
"Choice," "planning," "control," and other individual determinants of aging outcomes	Emphasizing how to improve social contexts: "Let's find creative solutions to ensure we can all thrive as we age…"
"Seniors," "elderly," "aging dependents," and similar "other-ing" terms that stoke stereotypes	Using more neutral ("older people/Americans") and inclusive ("we" and "us") terms
"Struggle," "battle," "fight," and similar conflict-oriented words to describe aging experiences	The Building Momentum metaphor: "Aging is a dynamic process that leads to new abilities and knowledge we can share with our communities…"
Using the word "ageism" without explanation	Defining ageism: "Ageism is discrimination against older people due to negative and inaccurate stereotypes…"
Making generic appeals to the need to "do something" about aging	Using concrete examples like intergenerational community centers to illustrate inventive solutions

Figure 1. Examples of Helpful Terminology Substitutions[3]

(Lundebjerg, 2017)

THE GERONTOLOGICAL SOCIETY OF AMERICA

Special Issue: 2015 WHCoA

Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future

Shih-Yin Lin, MM, MT-BC* and Frances Marcus Lewis, PhD, FAAN

School of Nursing, University of Washington, Seattle.

Dementia-Friendly Communities

MOMENTIA

Virtual Memory Cafes

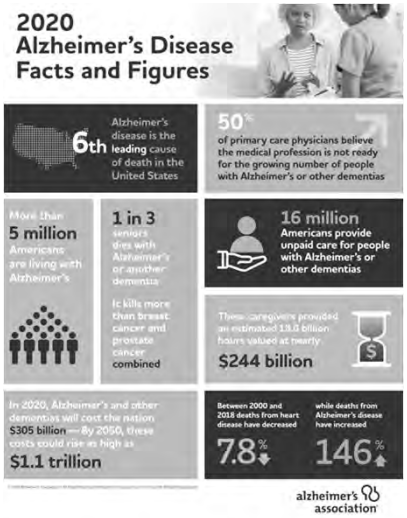
(Lin, 2015)

Who are the dementia caregivers?

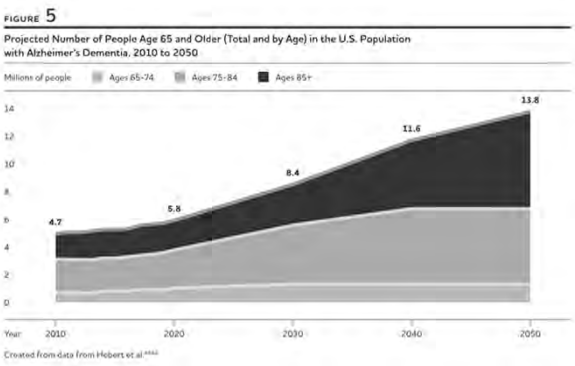
- 83% percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers
- Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.
- Most caregivers (82%) care for one other adult, while 15% care for 2 adults, and 3% for 3 or more adults.
- Approximately two-thirds of dementia caregivers are women.

(Alzheimer's Facts & Figures, 2020)

Why is this topic important?



Why is this topic important?



A new survey of primary care physicians appearing in the Alzheimer's Association 2020 *Alzheimer's Disease Facts and Figures* report finds nearly 9 in 10 primary care physicians (87%) expect to see an increase in people living with dementia during the next five years, but half (50%) say the medical profession is not prepared to meet this demand.

(Alzheimer's Facts & Figures, 2020)

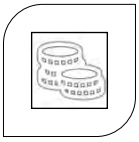
Ms. Jones and her daughter Vera

- Vera works and leaves Ms. Jones at home. She's recently cut back on her hours and thinks she may need to cut back more.
- Ms. Jones does not want anyone else caring for her.
- Vera puts out her food and medications before she leaves for work.
- Increasing concern for leaving Ms. Jones at home
- No other family
- Very close dyad

Guiding Questions

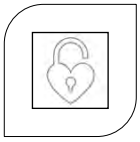
- Who are the dementia caregivers?
- What challenges do they face?
- How do we support dementia caregivers through their caregiving journey?

Dimensions of Dementia Caregiving

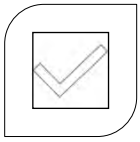


ECONOMIC

PHYSICAL HEALTH



EMOTIONAL HEALTH



DISTRESS / REWARDS

Type of Care Demands

- iADLs, then ADLs
- Medication administration/supervision
- Managing medical appts
- Managing the continuum of behavioral changes/symptoms
- Navigating support services
- Navigating finding in-home services, considering transitions
- Managing family issues
- Helping plan for future

ECONOMIC

Caregiving

- In 2019, caregivers of people with Alzheimer's or other dementias provided an estimated 18.6 billion hours of unpaid care, a contribution to the nation valued at $244 billion.
- Forty-one percent of caregivers have a household income of $50,000 or less.

(Alzheimer's Facts & Figures, 2020)

ECONOMIC

The average dementia caregiver earns <$50,000 a year

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Washington	353	402	5,268

(Alzheimer's Facts & Figures, 2020)

PHYSICAL HEALTH

- Dementia caregivers more likely to have more infectious episodes, slower wound healing, increased HTN/CAD
- A recent meta-analysis suggests that dementia caregivers had reductions in immune function and elevated inflammation.
- A 2017 poll reported that 27% of dementia caregivers delayed or did not do things to take care of a personal health problem
- Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers

(Roth, 2019)

EMOTIONAL HEALTH

- Depression diagnosis in up to 50% of all caregivers, more who perform more intense caregiving
- Behavioral symptoms as the “tipping point”
- 59% of family caregivers of people with Alzheimer’s or other dementias rated the emotional stress of caregiving as high or very high
- Spousal risk of dementia

(Collins, 2019)

Unravelling positive aspects of caregiving in dementia

DISTRESS V REWARDS

- Positive aspects of caregiving
  - personal accomplishment
  - mutuality in a dyadic relationship
  - family cohesion
  - personal growth and purpose
- Positive caregiving experience more likely to exist in the presence of three conditions:
  - personal and social affirmation of role fulfilment
  - effective cognitive emotional regulation
  - contexts which favor finding meaning in the caregiving experience.

(Yu, 2018)

Dementia Caregiver Assessment Tools

Caregiver Self-Assessment Questionnaire

How are you?

The Zarit Burden Interview

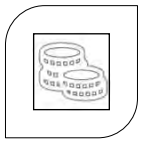
0: NEVER
1: RARELY
2: SOMETIMES
3: QUITE FREQUENTLY
4: NEARLY ALWAYS

Please circle the response that best describes how you feel.

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel stressed when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

- The provider who treats the care recipient is often the first health care professional to detect strain or burden because of dynamics in the caregiver–care recipient dyad.
- Routine screening is fundamental first step.

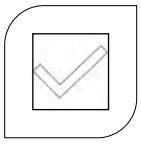
Dimensions of dementia caregiving for Vera



ECONOMIC

PHYSICAL HEALTH

EMOTIONAL HEALTH



DISTRESS V REWARDS

The Lancet Commissions

Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission

Gill Livingston, Jonathan Huntley, Andrew Sommerlad, David Ames, Clive Ballard, Sube Banerjee, Carol Brayne, Alistair Burns, Jiska Cohen-Mansfield, Claudia Cooper, Sergi G Costafreda, Amit Dias, Nick Fox, Laura N Gitlin, Robert Howard, Helen C Kales, Mika Kivimäki, Eric B Larson, Adesola Ogunniyi, Vasiliki Orgeta, Karen Ritchie, Kenneth Rockwood, Elizabeth L Sampson, Quincy Samus, Lon S Schneider, Geir Selbæk, Linda Teri, Naaheed Mukadam

- Caregiver distress closely linked to neuropsychiatric symptoms
- Highlights need for **effectively identifying, educating, and supporting distressed caregivers**
- STrAtegies for RelaTives intervention—manual-based coping intervention delivered by supervised psychology graduates—found continuing effectiveness for depressive symptoms in caregivers
- Specific interventions for family carers have long-lasting effects on depression and anxiety symptoms, increase quality of life, are cost-effective and might save money.

Lancet, 2020

Guiding Questions

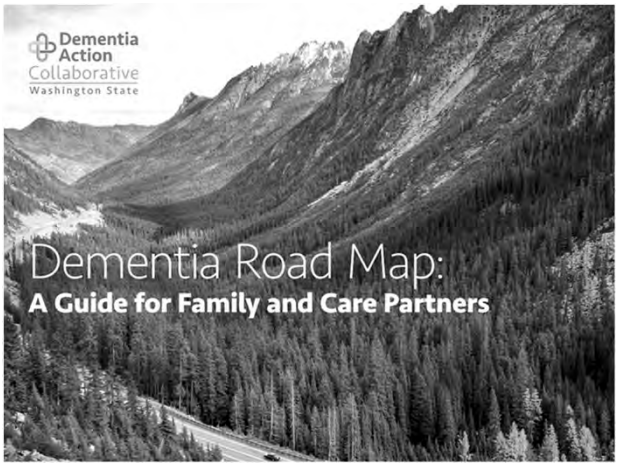
?

- Who are the dementia caregivers?
- What challenges do they face?
- How do we support dementia caregivers in their caregiver journey?

Supporting Caregivers Along the Dementia Care Journey

Diagnosis → Early-Stage → Mid-Stage → Late-Stage → End of Life and Grieving

Dementia Action Collaborative



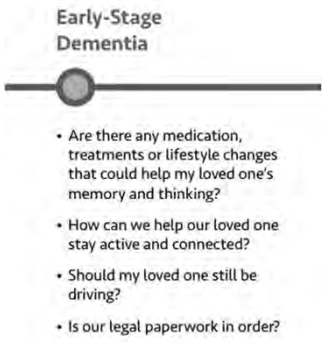
(https://www.dshs.wa.gov/altsa/dementia-action-collaborative, accessed 2020)

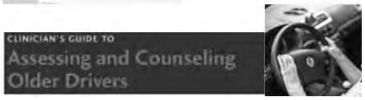
Step 1: Diagnosis of Dementia

- Fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records report that they do so.
- Missed opportunities to provide diagnosis
- Advance care planning: financial and health-related
- From time of diagnosis, much more could be done to integrate clinical care with community-based support.

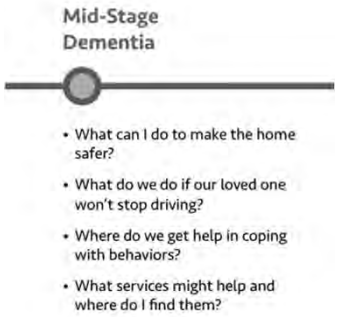
alzheimer's association

Step 2: Early-Stage Dementia





Step 3: Mid-Stage Dementia



- Community Living Connections (Area Agencies on Aging/AAAs)
- Alzheimer's association connection care consultation program
- Clinic based interprofessional teams
- Care models
- Advance care planning

Step 2: Late-Stage Dementia

- Cost of care without Medicaid
  - Home health aid $23/hour
  - Adult day health $75/day
  - Assisted living facility $4,000/month (menu)
  - Nursing home: $100K/year
- Medication deprescribing
- Respite care
- Advance care planning

Respite Care | DSHS
Respite care is a service where another trained person or staff at a facility provide planned, short-term care (a few hours to a few days) for your loved one so you have some time away from caregiving.
www.dshs.wa.gov

Family Caregiver Support Program
The Family Caregiver Support Program provides help and resources for those who provide unpaid care to a senior adult or and adult with a disability.

King County Caregiver Support Network
P.O. Box 34215
Seattle 98124
Website: https://www.communitylivingconnections.org/wecanhelp/caregivers/
Phone: 1-844-348-5464 (KING)
Alt. Phone: 206-962-8467

Step 2: End-of-Life

- What setting is desired and practical?
- Between 1999 and 2017, more Alzheimer's patients dying at home (less in nursing homes and facilities)
- Reminder that hospice supports but they still need 24-hour caregiving, particularly towards end of life, family members need coaching about how to use prn medications.
- Intensive supports needed over long period of time

(Trinh, 2020)

Step 2: When the Dementia Caregiver Grieves

- Positive grief experiences included
  - positive construction of memories
  - death as the end of suffering
  - relationship resolution
- Negative grief experiences
  - family member's decline as traumatic
  - caregiver role loss
  - unavailable support
  - difficulties creating a new life

(Supiano, 2020)

Model Programs for Person's with Dementia and their Caregivers

Design care for people with dementia by moving away from an approach that focuses on loss of abilities due to dementia to an approach that emphasizes the individual's unique needs, personal experiences and strengths.

(Alzheimer's Facts & Figures, 2020)

Model Programs for Person's with Dementia and their Caregivers

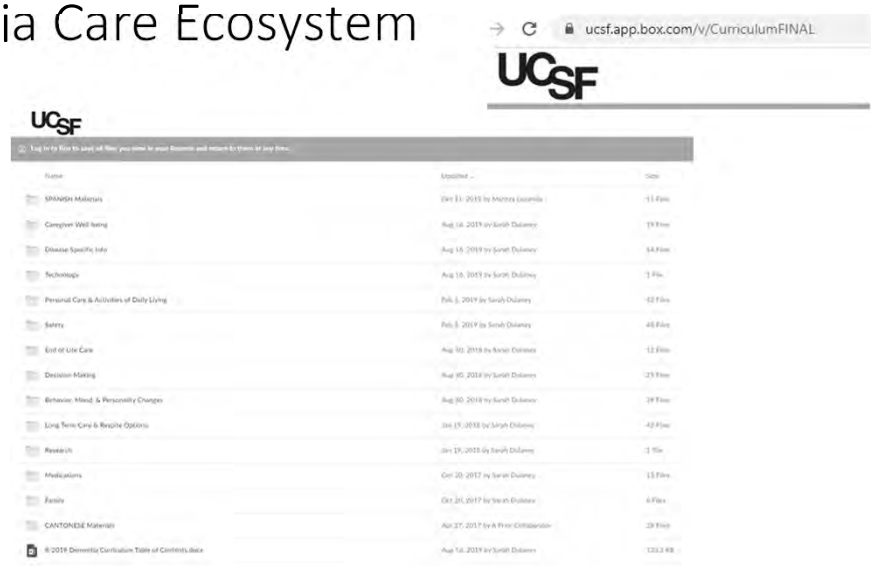
(https://www.uclahealth.org/dementia/, accessed 2020)

Model Programs for Person's with Dementia and their Caregivers

- Dementia Care Ecosystem

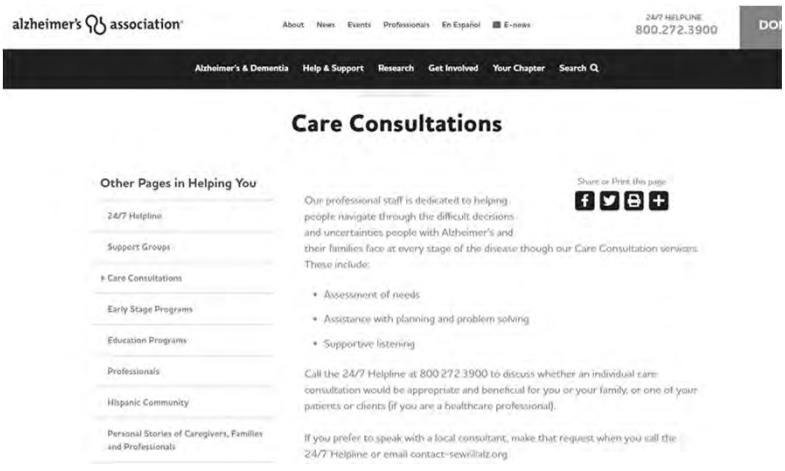
(https://memory.ucsf.edu/research-trials/professional/care-ecosystem, accessed 2020)

Dementia Care Ecosystem



(https://memory.ucsf.edu/research-trials/professional/care-ecosystem, accessed 2020)

The Alzheimer's Association



Model Programs for Person's with Dementia and their Caregivers

- Memory and Brain Wellness Center UW Medicine
  - Robust interprofessional services
  - Link to research opportunities for patients
- Interprofessional Geriatric Assessment Clinic at Swedish Medical Center SWEDISH
  - Geriatric medicine, nursing, pharmacy, social work, behavioral health
  - Individual session with caregiver at the time the person with dementia is getting cognitive testing

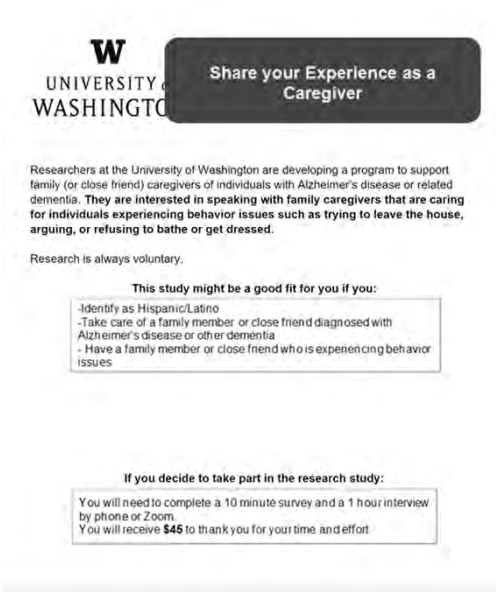
Dementia Caregiving in the Time of COVID-19

- Outreach
- Telehealth
- Physical distancing, social isolation
- Limiting exposure of caregiver, Backup caregiving
- Vaccinating both patient and caregiver
- ACP in the time of COVID
- Advocacy for being present if person with dementia hospitalized

When Dementia Meets the Coronavirus Crisis

Disruptions in routines and the need for hands-on care are among the special challenges for dementia patients and their caregivers.

(Halpert, 2020)



UNIVERSITY of WASHINGTON

Share your Experience as a Caregiver

Researchers at the University of Washington are developing a program to support family (or close friend) caregivers of individuals with Alzheimer's disease or related dementia. **They are interested in speaking with family caregivers that are caring for individuals experiencing behavior issues such as trying to leave the house, arguing, or refusing to bathe or get dressed.**

Research is always voluntary.

This study might be a good fit for you if you:

-Identify as Hispanic/Latino
-Take care of a family member or close friend diagnosed with Alzheimer's disease or other dementia
- Have a family member or close friend who is experiencing behavior issues

If you decide to take part in the research study:

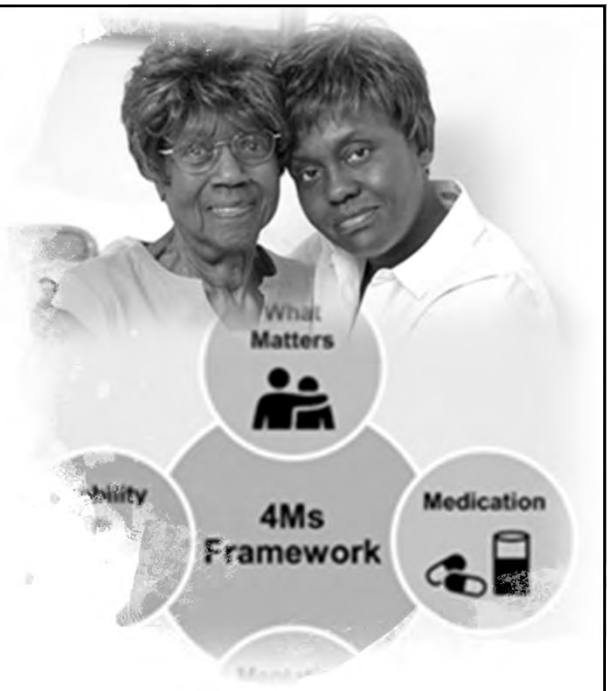
You will need to complete a 10 minute survey and a 1 hour interview by phone or Zoom.
You will receive **$45** to thank you for your time and effort

BIPOC Populations

- Black Community
  - The prevalence, incidence, and cumulative risk of Alzheimer's disease appears to be much higher in African-Americans than in non-Hispanic whites.
  - Racism/discrimination has a long history in the African American community and can affect trust building
  - Support from family and friends is associated with better self-rated health for African American dementia caregivers
- All BIPOC Communities
  - Address structural and institutional issues
  - Need to tailor caregiver interventions to mediate stressors, resources, and coping strategies based on caregiver preferences.

(Fawn, 2020)

Vera and
Ms. Jones

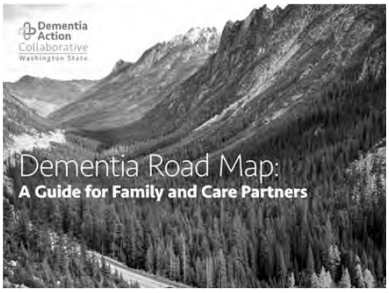


Guiding Questions

- Who are the dementia caregivers?
- What challenges do they face?
- How do we support dementia caregivers through their caregiving journey?

Conclusion

While we do not have disease modifying treatments for dementia, our collective role as an interprofessional team treating a person with dementia and their caregiver is critical.



Thank you!

- Carrie Rubenstein, MD
- carrie.rubenstein@Swedish.org