



# The Dignity - and Disruptions - of Dementia Caregiving

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## Today's Agenda

1. Thank Expert Contributors
2. Honor Family Caregivers
3. Recognize Federal Leadership & State Innovations
4. Acknowledge the Challenges of Family Caregiving
5. Discussion

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## Thank you!



- AARP
- Administration for Community Living
- Alzheimer's Association
- Caring Across Generations
- Centers for Disease Control
- Family Caregiver Alliance
- National Alliance for Caregiving
- UCSF Benioff Homelessness and Housing Initiative

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## 11+ million Americans are Dementia Caregivers



- Providing an estimated **18.4 billion** hours of unpaid dementia care to family, partners, kin, friends and neighbors in 2023
- Contributing uncompensated care valued at nearly **\$350 billion** in 2023 - the same value as the entire COVID-19 American Rescue Plan Act

[Alzheimer's Association 2024 Facts & Figures](#)

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## Who are Dementia Caregivers?

- Most caregivers are women, and the average age of caregivers is 49.4, with one-quarter between 18 and 34. [AARP Caregiving in the U.S.,2020]
- Caregiving roles vary by race, ethnicity, language, culture, LGBTQ+ identification, and income with disparate experiences and burdens.



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## The Dignity of Dementia Caregiving

How Family, Friends, Partners and Kin Describe Their Role

- Rewarding
- Fulfilling
- Satisfying
- Meaningful
- Spiritual
- Purposeful
- Sacred
- A privilege
- A blessing
- A responsibility
- A gift
- An honor
- An opportunity to give back



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## The Disruptions of Dementia Caregiving



- Health Impacts
- Mental Health Status
- Financial Pressure
- Preparedness
- Work Interruptions
- Elder Justice
- Housing Stability

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## Health Impacts



- 53% of (all) caregivers who responded to the CDC Behavioral Risk Factor "Caregiver Burden" Surveillance Survey indicated that a decline in their health compromised their ability to provide care.
- 40.7% of (all) caregivers report having two or more chronic diseases.
- 38% of dementia caregivers report physical stress.



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## Mental Health Status

- 59% of dementia caregivers report high to very high stress.
- 41% were socially isolated with no other family or friends to assist with caregiving.
- Dementia caregivers describe having no choice in their role and decreased social network.



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## Mental Health Status



The day care staff "asked me though if I considered suicide and I said yes [crying]. It's something I'm not proud about, but oh, I was tired."

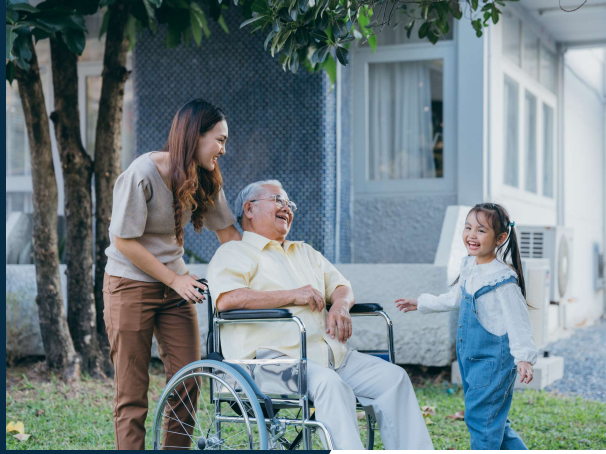
-Caregiver to participant in ARPA funded Alzheimer's day program

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## Financial Pressure

- Dementia Caregivers spend nearly double out-of-pocket
- \$12,388 annually vs. \$6,667 for other conditions



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## Financial Pressure



"...but the cost to provide caregiver services is really expensive. Here in the Bay Area, you're looking at, for 24/7 care through an agency... **\$15,000 a month, that's almost a quarter of a million dollars a year.** That is a lot of money, and I told you my folks have long-term healthcare insurance. If they needed 24-hour care, or if we were in that situation, the amount that my mom receives would cover less than a third of that total cost, so there is a crisis."

-ARPA-funded day center participant

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## Workplace Interruptions



- Nearly 6 in 10 caregivers are currently working (59 percent) either full-time or part-time.
- Dementia caregivers sacrifice health insurance benefits, sick/vacation leave, full-time work, career advancement, retirement contributions, Social Security credits, unemployment insurance



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## Workplace Interruptions



"I'd say, the biggest change in our quality of lives, I think, focus... We have peace of mind that, she's not trying to go out the front door, and that's really helped. I just started work and... I was thinking of, **should I take a leave of absence so I could do this properly and watch her properly.** To be able to actually start my career, my work, and still be able to do this [care for her], has been really life changing."  
-ARPA-funded program participant

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## Workplace Interruptions



When my mother was diagnosed with Alzheimer's seven years ago, my life changed dramatically. I quit my job, sold my house and moved in with her, and became her caregiver. Oh, and I'm a single mom to a teenage son, too. While I didn't think it would be easy, I underestimated the physical, emotional, and financial toll that caring for my mom would take. Before I became my mom's caregiver, I was working full-time as a paralegal, making a comfortable salary. Now I work part-time from home and my income has been slashed in half, in order to be there for my mom and manage her care and the seemingly endless doctor's visits and appointments. The costs of care add up – but right at the time when we need financial stability the most, I find myself worrying over every penny. **My own retirement security is now at risk; I turn 50 this year, but I cashed out my 401(k) to help cover some of my mom's medical bills.** I wish people understood how expensive caregiving can be. We live paycheck to paycheck.

-Heather Bolden, Farmington, MN, Caring Across Generations<sup>15</sup>

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## Training Challenges

Dementia caregivers perform intimate tasks, experience challenging, and face increasing demands as Alzheimer's disease progresses.

A Riverside, CA participant in the ARPA-funded CalGROWS training and stipends initiative shared her experience.



"I needed the money and heard about some kind of program to help caregivers financially."



"I've worked various jobs, but caregiving is where I'm happiest. I've always wanted to care for people."



"I've recommended it to friends and even my son, who cares for his grandpa with dementia. These courses give you the knowledge you need."

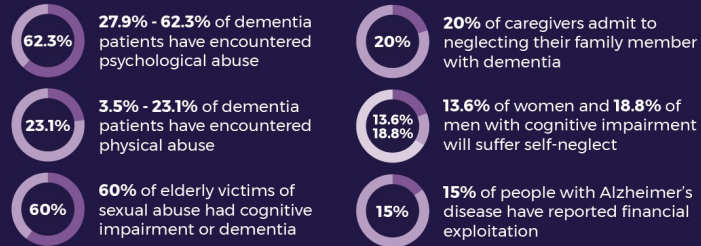
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## Elder Justice

### Dementia Increases the Risk of all Forms of Abuse



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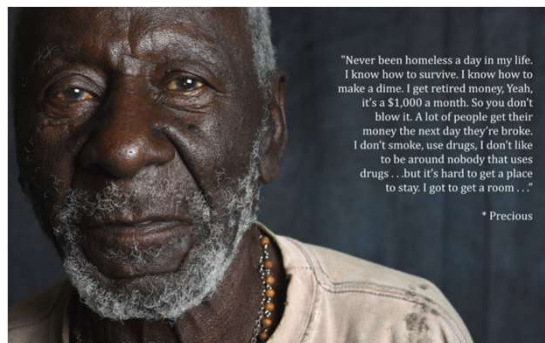
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## Housing Stability

The Homeless population is aging.

The proportion of single homeless adults who are  $\geq 50$

- 1990 - 11%
- 2003 - 37%
- 2023 - 48%



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## Toward a New Understanding

### The California Statewide Study of People Experiencing Homelessness - June 2023

Margot Kushel, MD  
Professor of Medicine, UCSF

- Median Age: 47
- 48% of single adults were 50+
- 41% of this group first became homeless at 50 or older
- Median warning before losing housing: 5 days

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## Federal LTSS Efforts Focused on Caregivers

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ARPA funding

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RAISE Family Caregiver Act

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National Strategy on Family Caregiving

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ACL Older Americans Act Final Rule & Reauthorization

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CMS Physician Fee Schedule

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CMS GUIDE model

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CMS Medicaid waiver programs with respite, home modifications and housing supports

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# Discussion

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