# At risk: the challenges of Alzheimer's and dementia for your women patients

By Juliet Holt Klinger, MA Senior Director of Dementia Care November 2021



brookdale.com

#### Why dementia is a women's healthcare concern

**Dementia is used to describe a wide range of symptoms** associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's is the most <u>common form of dementia</u>. The disease causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming serious enough to interfere with daily tasks.

Your female patients are <u>at risk</u>. Of the more than 6 million Americans living with Alzheimer's or dementia, almost <u>two-thirds</u> are women. Not only are women more likely to be <u>diagnosed with</u> <u>dementia</u>, including Alzheimer's, they are also <u>more likely to be caregivers</u> for those living with Alzheimer's and other dementias.

**The good news?** Over the past 10 years, a growing number of scientists, policymakers and organizations have begun to focus on why women are at the center of the dementia crisis. A new <u>report</u> recently released by AARP and the Women's Alzheimer's Movement (WAM) reviews years of data and findings to help explain why women are disproportionately affected by Alzheimer's disease. It also offers a roadmap and action plan to create meaningful change moving forward.



Approximately **13 MILLION WOMEN** in the US are either living with Alzheimer's or caring for someone who has the disease.



Almost **TWO-THIRDS** of Americans living with Alzheimer's are women.



Women in their 60s are more than **TWICE AS LIKELY** to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.

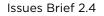


**MORE THAN 60%** of Alzheimer's and dementia caregivers are women. More specifically, more than one-third of dementia caregivers are daughters.



**Nearly 19%** of women dementia caregivers had to **QUIT WORK** either to become a caregiver or because their caregiving duties became too burdensome.

Source: 2020 Alzheimer's Association Facts and Figures Report, alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068\_





#### Why do more women develop Alzheimer's and other dementias?

At first, the disproportionate impact of Alzheimer's on women was <u>attributed to age</u>. Since women tend to live longer than men, and age is the greatest known risk factor for Alzheimer's, researchers thought age might help explain the gap. Now scientists aren't sure it's that simple.

According to a <u>new study</u>, middle-aged women are more likely than men to have brain changes related to Alzheimer's disease, as detected by imaging, even when there are no differences in thinking and memory. Researchers think this may be associated with hormonal changes due to menopause, specifically the loss of estrogen.

Scientists are also studying sex-specific differences in the architecture of the brain. For example, in a <u>study</u> released at the 2019 Alzheimer's Association International Conference (AAIC), researchers found that differences in the structural connections of a woman's brain may speed the spread of tau, a protein that clumps into tangles and may contribute to cell damage.

Biological factors may not be the only risk factors at play. Societal and cultural factors may also put women may be at a greater risk of developing the disease. <u>A recent study</u> found that work and family patterns, which have changed significantly over the last 100 years, might play a role in a woman's memory decline. Researchers found that women who participated in the paid labor force between early adulthood and middle age experienced slower memory decline in late life, building on previous research that associates work and education with higher levels of cognitive engagement.



Issues Brief 2.4





#### Implications of the caregiving role for women

#### Unpaid caregivers

The contributions of unpaid caregivers are often undercounted, which exacerbates the impacts on women. Nearly <u>83 percent</u> of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. And more than <u>16 million Americans</u>, almost half of all caregivers, provide unpaid care for people living with dementia. The financial value of unpaid caregiving is also often undervalued. In 2019, dementia caregivers provided an estimated <u>18.6 billion</u> hours of care valued at nearly \$244 billion.

When a family member is diagnosed with Alzheimer's or dementia, caregiving responsibilities <u>disproportionately fall to women</u>.

- Nearly **two-thirds of dementia caregivers are women**, and more than one-third are daughters.
- More than two-thirds of caregivers are married, living with a partner or in a long-term relationship.
- Surveys have found that approximately 25 percent of dementia caregivers are "sandwich generation" caregivers — they care not only for an aging parent but also for children under age 18.
- About one in three caregivers (30%) is age 65 or older.

Issues Brief 2.4



brookdale.com

#### What kinds of care and support are unpaid caregivers providing?

- Household chores, cooking, cleaning, shopping, errands and more
- Transportation to doctor's appointments
- Managing finances and legal affairs
- Managing medications and treatments for dementia or other medical conditions
- Physical assistance with bathing, dressing, grooming and feeding
- Helping the person walk, transfer from bed to chair, use the toilet and manage incontinence
- Preventing behavioral expressions including wandering, depressive moods, agitation and anxiety

Source: <u>alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068</u>

#### Impacts of caregiving

The responsibilities of caring for someone with dementia often fall to women, and the true cost of this care can be staggering — financially, emotionally and physically for your women patients.

#### **Financial impacts**

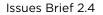
## Caregiving responsibilities impact women's careers and participation in the workforce.

- Nearly <u>19% of women</u> Alzheimer's caregivers had to quit work, either to become a caregiver or because their caregiving duties became too burdensome.
- <u>Three out of four</u> US workers have caregiving responsibilities, and most say these duties affect their work productivity. But only 24 percent of employers think caregiving affects worker performance.
- A recent study found women were <u>73% more likely</u> to leave the labor market, more than **five times** more likely to work part-time, and twice as likely to take time off because of caregiving needs.

"Despite all the progress we've made in recent years, one of the biggest risks to women's progress may be caregiving. Many management-level women are being pulled out of the workforce to care for their parents, and these are the very women who could help other women rise. Just as we have begun to question, 'Why always Mom?' with childcare, we should also now ask, 'Why always daughter?' with senior care."

#### Jay Newton Small

Author of Broad Influence and Time Magazine Correspondent Founder of MemoryWell and Caregiver for father with Alzheimer's





#### **Emotional and physical impacts**

In a <u>recent poll</u>, 45% of respondents indicated that caring for someone with dementia was very rewarding. Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also frequently report higher stress levels and poor health.

- Women caregivers may experience <u>higher levels of depression</u> and impaired health than their male counterparts.
- About 35% of caregivers of people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities.
- Approximately <u>59% of family caregivers</u> of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high.
- <u>Nearly half</u> of dementia caregivers indicate that providing help is highly stressful, compared with 35% of caregivers of people without dementia.
- Many caregivers also experience guilt and shame, emotions with debilitating effects.

# Tools to help your caregiver patients improve their well-being

#### Signs your patient may be feeling the strain of caregiving

- They begin to feel that no matter what they do, it just isn't enough.
- They talk about feeling isolated, like they are the only ones enduring this situation.
- Family relationships may begin to deteriorate.
- Caregiving interferes with work and social life to an excessive degree.
- They refuse to think of themselves, because that would be "selfish."
- Coping methods are unhealthy: over/under eating, drugs, alcohol, etc.
- There are no more happy times: only exhaustion and resentment.
- They see asking for help as a failure.



Issues Brief 2.4



## Here are some suggestions you can offer to your patients struggling with the strain of caregiving:

- **Give yourself some time;** understand that you will have a range of emotions. You may need assistance to accept the full trajectory of the disease process.
- Set limits for yourself, realistic expectations and stay focused on reality. Recognize what you can and cannot do.
- Share the responsibility of care. Enlist and allow others to help; for example, your sister might not do as good a job, but you need to trust her to help.
- Establish and set routines to give you both a sense of safety, security and stability.
- Take one day at a time, but prepare and plan for the future.
- **Understand your relationship with the person** you care for will be different, but it can still be meaningful and rewarding.
- Try to remember the good things about the person, and don't forget to laugh!

**Respite care is another valuable tool for your patients.** Some memory care settings and communities provide short-term respite care. Respite care can provide relief or breaks to help decrease stress, restore energy and offer balance in your patient's life. Respite care might also be another way to help introduce a person living with dementia to long-term memory care community. In-home services can also be helpful, especially for tasks that are easily outsourced. Volunteer and paid companion services, personal care or skilled health assistance are also valuable in-home services.



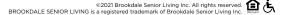


Juliet Holt Klinger, the Senior Director of Dementia Care for Brookdale Senior Living, is a gerontologist specializing in person-centered programs for people living with dementia. As an educator and program designer for more than 35 years, she has developed and operated programs for national companies representing both skilled nursing and assisted living levels of dementia care. Juliet provides strategy, development and innovation for Brookdale's dementia care service line and serves as the company's gerontological expert. Juliet is a longtime advocate for person-centered care and is a frequent presenter on issues related to dementia care at national conferences.

If you have questions about the impacts of dementia on your women patients, we can help. Reach out to a Brookdale Clare Bridge community for more information.

Issues Brief 2.4

522902 LMB





7