

Time to Act: Coming Together to Solve the Women's Alzheimer's Crisis

By Maria Shriver and Sarah Lenz Lock

It has been 10 years since the Women's Alzheimer's Movement formed to cast a spotlight on a global challenge that should concern us all: the extraordinary burden the diseases causing dementia place on women.

Women are much more likely than men to develop and be living with Alzheimer's Disease and other forms of dementia. They are also much more likely than men to be caring for a loved one with Alzheimer's or another serious cognitive impairment. African American and Hispanic women pay the greatest price of all.

Some initial progress has been made over the past decade, but not nearly enough, particularly as the world population ages, putting more and more women at risk.¹ The urgent need for solutions prompted us to convene what turned out to be a remarkable brainstorming session in Los Angeles in July 2019.

Through that event, AARP and the Women's Alzheimer's Movement brought together 75 dementia researchers, advocates, and policy experts to examine the current state of research, point out gaps in knowledge, and forge a path forward. With support from the AARP Foundation's A. Barry Rand Fund for Brain Health Research, this diverse group of stakeholders and experts — working separately on different parts of potential answers — agreed to collaborate on a strategic plan to transform the issue of women and dementia in the coming decade.

We are now finalizing the details of that plan — what will be a global strategy to help all women who are contending with Alzheimer's and dementia, regardless of income, ethnicity, education, or cultural background. Our report released May 21, 2020, *It's Time to Act: The Challenges of Alzheimer's and Dementia for Women* highlights critical steps we all need to take to drive progress in women's brain health over the next decade. You can watch the video replay and download the full report here: <https://www.aarp.org/health/brain-health/global-council-on-brain-health/womens-report/>. *It's Time to Act* serves as an unprecedented call to action by identifying explicit steps that stakeholders must take to address the gender inequities of dementia and more effectively support women on this issue.

The report calls for policy initiatives, public education, and more equitable research. The findings also detail lifestyle choices women can make to fortify their brain health and help protect themselves.

What We Know about Women and Dementia

For too long, women have borne a disproportionate share of the burden associated with Alzheimer's and dementia — the latter being a more general term that covers a range of conditions that impair memory and other basic thinking skills people need to live independently.

Alzheimer's disease is the most common form of dementia.² Of the 5.8 million US adults living with Alzheimer's disease, about two-thirds are women.³ Women also provide more than 60 percent of the dementia caregiving responsibilities in the US.⁴ Globally, almost 50 million people have dementia,⁵ and it strikes more women than men in all regions of the world.⁶

We also now know that the greater incidence of Alzheimer's among women cannot be explained solely by the fact that women generally live longer than men. For many years, scientists assumed it was that simple. But this view failed to consider the many gender-based factors that may influence brain health. Until this century, women were generally left out of clinical trials, and sex differences were widely ignored in research questions.

We are pleased to report that this flagrant neglect has started to lessen. Women now represent 52 percent of participants in clinical trials funded by the National Institutes of Health (NIH), and NIH research studies increasingly consider differences based on gender, ethnicity, and age.

What We Still Need to Learn

Nevertheless, the long legacy of overlooking women in the scientific research has left vast gaps in knowledge that are only now starting to be investigated. In recent years, scientists have started to consider the various factors that may signal a woman is at risk for Alzheimer's or other related brain disease; they have also started to

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explore the complex pathways to dementia from a gender-based perspective.

The hormonal changes that affect women in midlife, for example, have emerged as one of the promising areas of investigation. That is because the drop in estrogen around menopause disrupts the female brain's ability to utilize glucose, which is the brain's main fuel. Brain scans comparing women and men in midlife have revealed that women's brains often have more plaque, more atrophy, and less connectivity — all warning signs of potential impairment later in life.

Such insights may help doctors identify women who are at risk and point to future treatment options. But more research is needed.

Scientists also need to acquire a greater understanding of genetics and dementia, specifically how certain genes may indicate a woman may be at higher risk and how to mitigate those risks. While researchers have long known that the gene APOE4 raises the risk of Alzheimer's in both women and men, it seems to be more dangerous in women, particularly those ages 65 to 75.⁷ Other genes are also being studied as risk factors from a gender perspective.

Sex-based links between dementia and certain conditions also await further study. For example, correlations have been found between dementia and such conditions as hypertension, depression, and high stress levels — all of which are more common among older women than older men. From science we need actionable

insights on such issues to prevent, delay, and minimize the impact of dementia on women, and we need doctors to be more aware of these links as they work to keep patients healthy.

A Global Concern: Social Determinants of Health

Another mystery is why certain population segments — in many cases, those with lower incomes and those that historically have been underserved — have higher rates of dementia. In the United States, for example, African Americans are twice as likely to develop Alzheimer's than Whites, and Hispanics are 1.5 times more likely to develop the condition, according to the Alzheimer's Association.⁸ Worldwide, approximately 60 percent of people with dementia live in low- and middle-income countries. Experts project that future increases in the incidence will be sharpest in developing countries with the fewest resources to address the issue.⁹

Along with such data comes evidence that societal influences that affect some communities more than others play an important role, perhaps interacting with genetic or other risk factors. Such influences include those that come earlier in life as well — factors including access to good schools, nutritious food, health care, and a healthy environment.

Cutting-edge research, meanwhile, is now exploring the effects of poverty, stress, and trauma

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on brain health throughout the lifespan. Those factors, of course, apply to both women and men, yet in many cases women suffer greater impact. Women typically carry the lion's share of caregiving responsibilities for their families while earning far less than men — making these economic and emotional challenges a potentially greater source of stress throughout their adulthood. For example, in India and Nepal, 84 percent of caregivers (due to all causes) are women, the vast majority of which are of working age.¹⁰

We have long known that exercising the body is a valuable way to support brain health. Researchers are now focusing on the benefits of exercising the brain itself. Growing evidence suggests that individuals with higher levels of education and career attainment develop a cognitive reserve that helps shield against dementia in old age. Men have historically held advantages over women in such areas, as have the affluent over the poor. Therefore, greater equity could yield far-reaching health benefits.

Far more research is needed on these issues. Many questions remain about the basic causes and ways dementia develops, and why it is more common in older women than men. The road map for meaningful change must include action on many fronts, including social policy, public awareness, access to quality and equitable health care, and family caregiver support in all communities.

A Strategic Plan to Conquer the Problem

Our strategic plan highlights crucial ways to achieve the kind of progress for women on the Alzheimer's and dementia front that is so long overdue. As the plan details, by working together, we can achieve the following:

1. Eliminate the stigma of dementia. All of society must recognize dementia as a public health problem for which women pay an exceptional and disproportionate price. Dementia is not a normal feature of aging. All of us, including policy makers, researchers, health care providers, communities, and individuals, have a role to play in fixing this inequality.
2. Empower women to promote their own brain health. A growing body of research suggests that a healthy lifestyle — based on good nutrition, exercise, learning, stress management, and careful monitoring of health conditions — can cut the risk of dementia by up to a third. Women should be encouraged to act on this hopeful and empowering information.
3. Invest in research to learn more about the causes of dementia in women, including the underserved. Scientists must accelerate efforts to understand gender-based differences

in dementia and why some women are more resilient to cognitive decline than others. Such knowledge is needed to develop better treatments for all.

4. Enhance public and private support for family caregivers. All family caregivers should have their own health care coverage and the training they need to empower them to provide quality care for their loved ones, as well as local services that can give them much-needed respite. Employers should provide paid leave for employees who also provide care at home.
5. Train health care providers to better recognize and treat cognitive decline in older women. Physicians should take proactive steps to promote well-being and implement evidence-based, person-centered care that optimizes quality of life for all who live with dementia.

Our brainstorming session in Los Angeles was an inspiring moment, and we expect that it will turn out to have been a pivotal one as well. But it was just one step in a much larger effort. The quest we are leading must continue until we finally conquer the gender disparities of dementia, the inequities among population groups, and ultimately the disease itself.

It has taken too long to answer the call we first sounded 10 years ago. Let's finally address the scientific questions that have been overlooked and enact the policies and treatments that will help women and families around the world. Now is the time to act.

Countless lives depend on it. ●

¹ While the global demographic achievement of more people living longer is to be greatly celebrated, increasing age is the biggest known risk factor for dementia in both women and men. As longevity increases, the numbers of people living and coping with dementia is projected to soar. The World Health Organization predicts that 152 million people will be living with dementia by 2050. See <https://www.who.int/news-room/fact-sheets/detail/dementia>

² Other common forms include vascular dementia, Lewy bodies dementia, and frontotemporal dementia, and it frequently appears as mixed types. <https://www.who.int/news-room/fact-sheets/detail/dementia>.

³ <https://www.alz.org/alzheimers-dementia/facts-figures>

⁴ Caregiving in the U.S., 2020. Washington, DC: National Alliance for Caregiving and AARP Public Policy Institute, May 2020, p. 10. Twenty-six percent of U.S. caregivers say their recipient is living with some type of dementia, up significantly from the 22 percent reported in 2015. Id. at p. 28.

⁵ <https://www.who.int/news-room/fact-sheets/detail/dementia>.

⁶ <https://www.alz.co.uk/women-and-dementia>

⁷ <https://news.usc.edu/126237/genetics-put-some-older-women-at-higher-risk-than-men-for-alzheimers/>

⁸ https://alz.org/alzheimers-dementia/facts-figures?_ga=2.240833856.2117751363.1582902744-100135955.1581782763

⁹ See <https://www.who.int/news-room/fact-sheets/detail/dementia> and <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5370095/>

¹⁰ https://www.embracingcarers.com/content/dam/web/health-care/corporate/embracing-carers/media/infographics/us/Merck%20KGA%20Embracing%20Carers_White%20Paper%20Flattened.pdf



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