



It's Time to Act

The Challenges of Alzheimer's and Dementia for Women

A **roadmap** for meaningful change in the **next decade**

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Foreword

Women and Alzheimer's. In 2010, I had no idea that this subject would become my mission, but it has. It was exactly ten years ago when I first learned – and reported – that Alzheimer's disproportionately impacts women, not just because we live longer – but for a myriad of other, so-far elusive, reasons. Why? Why do women make up 2 out of 3 cases of Alzheimer's? What is it about women's brains that makes them more susceptible to Alzheimer's and dementia than men's brains?

Ten years later, even though we've made some progress, we still can't answer those questions. But like others in this report, I keep asking and I keep pushing. Where have we not yet looked? What is it we still need to understand? When will we see progress?

In many ways, history, culture and science have all conspired to keep us from getting answers to these questions. Governments at every level didn't make Alzheimer's research a priority in men, much less in women. The public falsely accepted that "senility" was a natural part of aging. And scientists made assumptions that women were, by and large, smaller version of men. All of these factors have led to an enormous gap in knowledge about the nature of this disease and why it impacts women at higher rates than men.

Women bear the added financial and emotional brunt of Alzheimer's by





making up the majority of caregivers for those who have it. The numbers threaten to bankrupt us as a nation on every level as we look to the future and estimate that millions more around the world will be diagnosed with impaired brain health, perhaps fatally.

There is some promising news. Over the past 10 years, a growing number of scientists, policymakers and organizations have joined in our efforts to address why women are at the center of this crisis. They are dedicated to closing the research gap in knowledge. They are working to crystallize a new path forward in research, medicine and public policy. They are committed to solving the mystery of women and Alzheimer's.

That is what this report is about. It is the outcome of two organizations dedicated to women's global health collaborating with some of the brightest minds around this issue to chart a new and bold course for the future of global brain health. The Women's Alzheimer's Movement (WAM) worked with the AARP 10 years ago as we first confronted the disproportionate impact of Alzheimer's on women. We came together again last July to invite top researchers and policy makers from around the world to a brainstorming session in Los Angeles. It was an incredible meeting as dozens of leaders in their respective fields joined together to lay out their understanding of where we find ourselves today and where we need to go. This report's Strategic Plan on how we can get there comes from this collaboration.



As you will read, we've come a long way in recognizing how unique women's brains are, and how and why we now understand that biology, lifestyle and economic circumstances all contribute to the high rate at which women develop these diseases of the brain. But while we understand a lot more about women's brain health 10 years later, the sobering state of affairs remains that we still have no vaccine, no treatment and no cure for this disease – for women or for men.

That lack of progress is absolutely unacceptable. What follows here is a call to arms, a serious plea for action and commitment from our leaders in government, business and in our communities. We are saying: *Enough! We cannot afford to lose more brains to this disease. Let's support our best, most innovative scientists and doctors, our most creative and compassionate leaders, and pair them with the resources they need to finally change the trajectory of this disease.*

If the Covid-19 crisis has taught us nothing else, it is that we must be prepared for an epidemic that data predict – and science accepts – as inevitable fact. We cannot wait for more generations of women to lose their brains and lives to Alzheimer's. We cannot allow dementia to continue to claim the lives of our mothers, aunts, grandmothers, sisters, nieces, daughters and friends in record numbers.

We have to act, we have to act now, and best of all, we have laid out a plan to help us do so.

Maria Shriver

Call to Action

Six million Americans have Alzheimer's disease or another form of dementia, and the numbers are soaring around the world – forever changing the lives of individuals and their caregivers.

Yet this challenge does not fall evenly across the population. Far more women become cognitively impaired than men, and far more women provide care to those who do, at great personal cost. Low-income, underserved communities, often of color, are hit hardest of all.

These disparities have been known for years, yet society has failed to address them. It's time for that to change, and AARP is working to make that happen in collaboration with leading brain health researchers and women policy advocates from around the world.

In July 2019, AARP and the Women's Alzheimer's Movement convened an extraordinary session to spotlight this challenge. With support from AARP Foundation's A. Barry Rand Fund for Brain Health Research, 75 leading experts gathered to examine the state of research and point the way forward. Our group included scientists, policymakers and advocates, all on the cutting edge of dementia policy. The discussions were filled with insights and recommendations we can act on.

This report is the product of that brainstorming session, with thoughtful input from others who later joined the effort. It lays out the task before us and offers a Strategic Plan to conquer the inequities of dementia that are so harmful to women.

Our plan highlights five critical steps designed to:

- 1. Eliminate the stigma of dementia.** Stigma stands in the way of diagnosis and quality care for this serious, public health problem.
- 2. Empower women to be brain healthy.** Science has shown that we can all do a great deal to promote our own brain health.
- 3. Ensure that research is inclusive.** Researchers must learn why dementia affects so many women and underserved communities, and they should report such data in their findings.
- 4. Support family caregivers.** All family caregivers should have access to training and local services that help them provide better dementia care. They should have paid leave and health care benefits.
- 5. Improve medical training for dementia.** Health care providers must do a better job of addressing, spotting and treating cognitive decline in older women.

We can't simply sit back and wait for a cure. With each passing day, thousands of women and men begin their private struggle with dementia. Society can do much more to improve their care and help people keep their brains healthy through the course of their lives.

AARP is committed to helping. The disparities in dementia reflect a legacy of neglect that must be changed, once and for all.

Achieving these goals will improve lives all over the world.

Jo Ann Jenkins

WOMEN their BRAIN HEALTH, ALZHEIMER'S, and DEMENTIA

A BRAINSTORMING SESSION ABOUT



RESEARCH PANEL

POLICY PANEL

Imagine all your memories...

WHY? NOT!

FIGHT FOR RESEARCH! ACCELERATE MOVE BEYOND THE BLINDS

IT'S TIME!

UNDERSTAND

BLANK SLATE - are gone

WOMAN EDUCATE RESEARCH COLLABORATE

WHY?

60% OF CAREGIVERS OF PEOPLE WITH DEMENTIA ARE WOMEN

WOMEN CARRY 76% OF THE ECONOMIC BURDEN FOR COST OF CARE

OUR BEST BET IS PREVENTION

THIS IS IMPORTANT TO OUR AARP MEMBERS!

INCREASE RESEARCH \$2.3 BILLION

8900 STEPS PER DAY SLOWS COGNITIVE DECLINE

SEX DIFFERENCE IS STUDIED MORE

WE HAVE MORE TALK

WE START TO PLEASE OURSELVES - DON'T ASK FOR ASSISTANCE

IT'S NOT THAT WE LIVE LONGER

HORMONE THERAPY SHOULD BE PERSONALIZED

WE NEED TO RECONCILE ALL WHITE STUDIES

EARLY PREVENTION

IT'S A WOMAN'S DISEASE

PREVENTION MEDICINE

60% OF LIPID

WE NEED MORE COMMUNICATION

- HYPERLIPIDEMIA IMPAIRS COGNITIVE FUNCTION
- 8900 STEPS !!
- WALK POSITIVELY IMPAIRS COGNITIVE FUNCTION
- STAY YOUNGER - AS EARLY AS 40
- DON'T REMOVE YOUR OVERSICUS PER MENOPAUSE

NOT ENOUGH WOMEN WHO PARTICIPATE IN TRIALS

HORMONE THERAPY

CORPORATE MEDICAL LEAVE FOR CLINICAL TRIALS

PAID FAMILY LEAVE

FINANCIAL SECURITY WHEN RETURNING TO WORK

LIVE DEBATE AT THE NATIONAL LEVEL

TALK TO CONSUMERS

OPTIMIZE HEALTH

HOPEFUL POSITIVE

WE NEED TO BE ABLE TO TAKE THE TREATMENT OF CAREGIVERS

NO REVENUE NOT WILLING TO PAY FOR IT

CLOSE THE EVIDENCE GAP

TEACH OUR SCIENTISTS TO COMMUNICATE

IT'S BEYOND DEMENTIA... COGNITIVE HEALTH!

ARE WE ASKING THE RIGHT QUESTIONS?

TO POLICY MAKERS OUTSIDE THIS ROOM

CREATE A NEW BUSINESS ECOSYSTEM

NOT FINANCING OUR CURRENT SYSTEM

WHAT ARE ALL THE RIGHT SUPPORT CARE PROVIDERS?

CAREGIVER

THE DISEASE ALWAYS WIN.

WE WERE UNPREPARED

- PHYSICALLY
- INTELLECTUALLY
- EMOTIONALLY

WHOLE LIFE + WHOLE FAMILY DISEASE

24 HOURS / 736 DAYS

HOPE & POSITIVE MESSAGES ARE CRITICAL!

Rep's commit to work together

graphic footprints

Sophia Lang is the graphic artist who captured our collaboration's brainstorming to create awareness and empower women to tackle the challenges of dementia. July 16, 2019 Los Angeles, CA

Executive Summary

In the United States today, 5.8 million individuals live with Alzheimer's disease, about two-thirds of them are women¹ and the numbers are projected to soar. At current rates, 13.8 million Americans will be living with dementia by the middle of century,² and most of them will be women.

Dementia isn't a specific disease. Rather, dementia describes a group of symptoms related to memory, thinking and social abilities interfering with their daily functioning. Alzheimer's disease is the most common cause of a dementia in older adults, but there are a number of types of dementia, and they sometimes coexist. Women shoulder a wildly disproportionate burden in every single one of these diseases, which may rob them of independence, memories, their self-identity, and in the case of Alzheimer's, their lives.

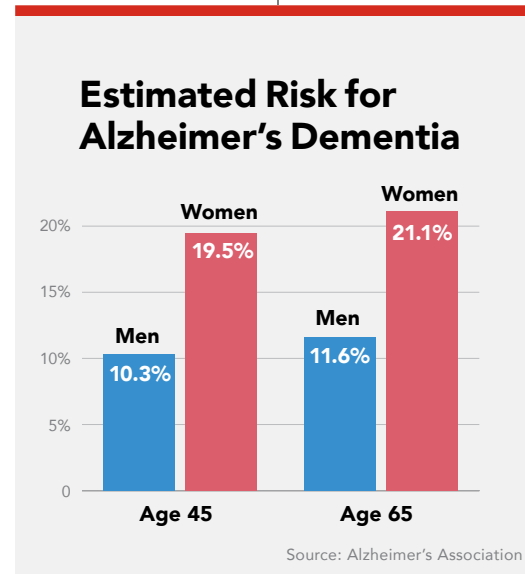
Health care providers should make a higher priority of spotting dementia early, distinguishing among its different forms, and discussing it sensitively with their patients. Once it is diagnosed, dementia may already be more advanced in women than men, and it may progress more rapidly. The idea that more women have

Alzheimer's than men – for the simple reason that women live longer than men – has been exposed as a myth.

Yet years of neglect by researchers – into women's health in general and Alzheimer's, specifically – have left critical gaps in knowledge about the gender differences in dementia. We need to know more about how risks, preventive measures and the course of disease differ for women and for men.

What *is* known, however, makes clear the imperative need for action:

- The lifetime risk for a woman to develop Alzheimer's (after age 45) is estimated at one in five; for men it is one in 10.³



- Based on current trends, more than 9 million women will have dementia by the middle of this century.
- Women make up more than 60% of dementia caregivers,⁴ and their numbers may soar in the coming years. Such dedication is invaluable to their loved ones and society, but it takes a tremendous toll on the caregiver's health and finances.
- Older African Americans are twice as likely to have Alzheimer's as older whites. Older Hispanics also have an elevated risk – about 1.5 times that of whites.⁵

“Putting the spotlight on better brain health will improve lives for everyone – but it will make the greatest difference for women, because women bear the heaviest burden for dementia, and underserved communities pay the highest price of all.”

SARAH LENZ LOCK

SENIOR VICE PRESIDENT, AARP; EXECUTIVE DIRECTOR OF THE GLOBAL COUNCIL ON BRIAN HEALTH



- Younger women are at risk, as well. While still rare, diagnoses of early onset Alzheimer’s (age 30 to 64) climbed 200 percent between 2013 and 2017, and women represented 58 percent of the new cases.⁶

Closing the gaps in our understanding will require new, gender-based research into biology, lifestyle choices and social policies that affect women. Some risks, such as depression and anxiety, affect both sexes but are more common in women. Others, such as a decline in estrogen at midlife, apply to women alone. Genetics, changes in women’s brains over time, and variables related to reproduction, including pregnancy and childbearing, all need to be studied further.

Yet scientific advances, crucial as they are, will not provide all the answers. The roadmap for meaningful change calls for action on many fronts, including social policy, public awareness and delivery of quality, equitable health care to communities that need it the most.

More should be done to ensure person-centered care that reflects the wishes of people living with dementia. Greater support is needed for individuals who are managing cognitive challenges on their own, as well as for caregivers who help their loved ones.

Belatedly, research efforts are now underway that will begin to address these challenges. We now understand that women have the most at stake in the battle against Alzheimer’s and all dementias. But more is needed to support women in this effort.

This report is a call for women to take ownership of their brain health and help lead the way to progress that has taken far too long. Doing so will improve the lives of women and men throughout the world – including generations yet to come.

It is time to act.



What We Know Today: Women and Dementia

“With aging there can be a decline in the brain’s ability to generate the fuel it needs. The key is maintaining the body’s system of glucose metabolism, and that entire process in women is regulated by estrogen.”



ROBERTA DIAZ BRINTON, PH.D.

DIRECTOR, CENTER FOR INNOVATION IN BRAIN SCIENCE, UNIVERSITY OF ARIZONA

Alzheimer’s disease follows a relentless course for all who experience it, regardless of gender. This is a reality for societies around the world. The costs to patients, families and society are astronomical and rising. There is no cure.

Yet dementia is a fact of life for women much more than for men. Two out of three older adults with dementia are women, and women make up a similar proportion of unpaid dementia caregivers, according to the Alzheimer’s Association.

For many years, women’s higher dementia numbers were generally seen as a consequence of living longer than men. But that view looks increasingly doubtful. Evidence has emerged that points to women’s biology and a range of social factors that may influence the emergence of dementia. After years of neglect, and thanks to requirements in the 1990s⁷, more women are now participating in federally funded clinical trials. Unfortunately, it is still rare for results

to be reported by sex. But researchers are starting to focus on gender-related factors and exploring whether they could lead to treatments.

Significantly, scientists have begun to study changes in women’s brains that occur in midlife that appear to signal an increased danger of dementia when they are older. Women’s genetic risks are gaining attention, as is their response to chronic disease and larger social factors, such as access to education, career attainment, economic stress and exposure to trauma. However, far more study is needed. Many questions remain about the causes of dementia in women, its incidence and how it progresses.

Issues of fairness and equity to underserved women have also been overlooked. Little research has been conducted to explain why African Americans, Hispanics, and women with low income and less education have higher rates of dementia – a serious gap in the knowledge base.

WHAT WE KNOW TODAY

These inadequacies call for a robust, multi-pronged response. Advocacy, education and research are all required to help women and their families maintain the best possible quality of life. Women's brain health – and how it can change through the course of a lifetime – is fundamental to women's health overall.

The costs of treating dementia in the United States are projected to reach \$368 billion in just 20 years, and 70 percent of those costs are for treating women, according to the Milken Institute.⁸

Yet even such a large dollar figure cannot begin to convey the scope of the human problem and the broader challenge for countries around the world.

In the United States today, two-thirds of older adults with Alzheimer's disease are women⁹ and the numbers are projected to soar. At current rates, 13.8 million Americans will struggle with dementia by the middle of this century.¹⁰ In some cases, individuals will live with the disease for many years.

The lack of progress in treating Alzheimer's stands out in contrast to advances against other major diseases. To give just one example, deaths from Alzheimer's on death certificates have increased 145%



in this century, while recorded deaths for heart disease fell 9% during that same period.¹¹

Dementia is the fifth leading cause for those age 65 and over,¹² and kills more women than men at any age.

The Impact is Greatest on Women

While Alzheimer's and other forms of dementia exact a tremendous cost on all of society, they present a particular challenge for women. Once diagnosed, decline may be more precipitous for women. And women are much more likely than men to serve as unpaid, dementia caregivers, an often exhausting role that may prove costly to their finances and health.

The toll of dementia on women can be gauged in many ways:

- The lifetime risk for a woman to develop Alzheimer's (after age 45) is estimated at one in five; for men it is one in 10.¹³
- Based on current trends, more than 9 million women will have dementia by the middle of this century.
- More than 60% of caregivers for those with dementia are women¹⁴ and their numbers will increase as the patient load soars in the coming years.

These numbers tell a story that is little known. By the time a woman reaches her 60s, she has more than twice the risk of developing Alzheimer's disease as breast cancer.¹⁵

Women who have reached age 65 face a higher likelihood of death from Alzheimer's than they do from diabetes, accidents, kidney disease, influenza or pneumonia. At age 85, it is the second leading cause of death for U.S. women, behind only heart disease.¹⁶ In the United Kingdom and Australia, dementia is the Number One cause of death for women.

Alzheimer's is the Leading Cause of Dementia

Dementia can be defined as "the loss of cognitive functioning – thinking, remembering, and reasoning – and behavioral abilities to such an extent that it interferes with a person's daily life and activities."¹⁷

The term often refers to [Alzheimer's disease](#), which is the most common form of dementia among older individuals. It was a cause of death in almost half the cases of dementia in 2017, according to the U.S. Department of Health and Human Services,¹⁸ and some experts have pegged the figure at closer to 70 percent.

Besides Alzheimer's, dementia may be caused by health problems that include:

[Frontotemporal disorders](#), caused by damage to the brain's frontal and temporal lobes;

[Lewy Body dementia](#), caused by abnormal deposits of the protein alpha-synuclein in the brain;

[Vascular injuries](#), including those caused by stroke;

[Mixed dementia](#), arising from a combination of problems, such as Alzheimer's and vascular.

End of a Myth: Longevity Alone Does Not Explain the Numbers

People used to think that more older women faced dementia than men for the simple reason that women often live longer. But we are learning that may not be the case.

At age 65, a woman in the United States is expected to reach her mid-80s – two-and-a-half years longer than life expectancy for a man of 65.¹⁹ In some parts of the world, the longevity gap is even wider. While age is the greatest risk factor, it is not the only one. Researchers have discovered that gender-based factors also correlate with dementia, including physical changes to the brain before symptoms of impaired cognition appear.

In one important development, scientists have recently identified changes in the brains of pre-menopausal women linked to a decline in estrogen that look like warning signs. Such hormonal changes “potentially diminish the brain’s ability to resist diseases like Alzheimer’s,” neuroscientist Lisa Mosconi writes in her new book, *“The XX Brain,”*²⁰ adding that such changes associated with menopause may “generate forgetfulness, memory lapses, even cognitive slippage.”



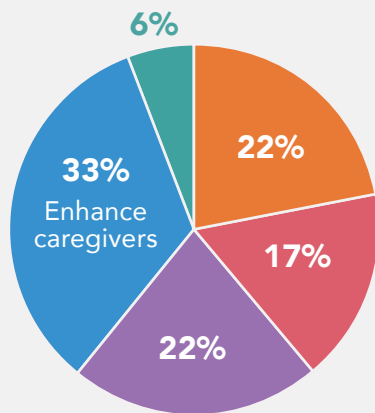
Researchers are also investigating differences in the progression of illness. A Duke University study of men and women with modest cognitive deficits found that women declined faster than men, both by measures of mental acuity and quality of life.²¹

Other scientists are focusing on gender-based differences in memory that may mask the emergence of dementia in women. One study found that at earlier stages of disease, women perform better than

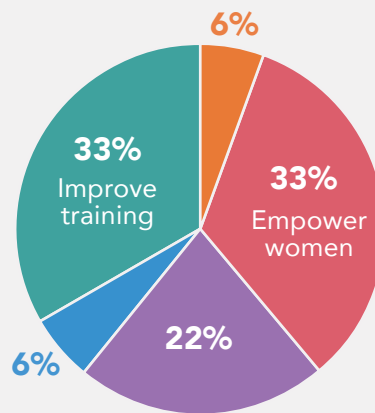
Brainstorm Survey Highlights

We surveyed our brain health collaborators asking them to evaluate which of the five action steps were most likely to achieve the outcomes we hoped to accomplish. The results differed based upon the desired outcome. Our experts said that the action likely to make greatest impact for vulnerable and underserved women was to enhance support for family caregivers. But this was closely followed by other actions of eliminating stigma and investing in research. When we asked

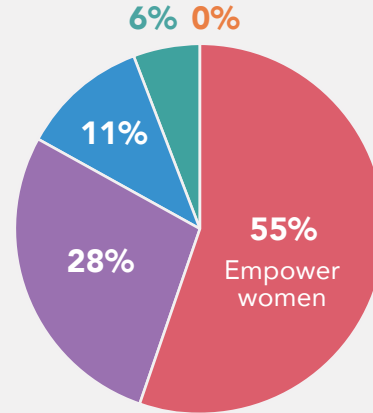
which action could be achieved most quickly, there was a tie between improving training for health care providers and empowering women to promote their own brain health. But by far and away, the greatest area of agreement amongst our survey respondents was that empowering women to promote their own brain health would result in the biggest improvement for women dealing with the challenges of dementia by 2030.



Which action will help **vulnerable and underserved** women dealing with the challenges of dementia the most?



Which action to help women dealing with the challenges of dementia would we be able to **accomplish most quickly**?



Which action will result in the **biggest improvement** for women dealing with the challenges of dementia **by 2030**?

Key to answers

- Eliminate the stigma of dementia
- Empower women to promote their own brain health
- Invest in brain health research that explores sex-based differences
- Enhanced support for family caregivers
- Improve training for health care providers

18 respondents
Percentage values are rounded

WHAT WE KNOW TODAY

men on verbal memory tests. This trait is significant, because it can conceal memory problems and lead doctors to overlook them.²² Once diagnosed in an older woman, dementia may be more advanced than for men, and it may progress more rapidly.

Gender-based differences in genetics provide further evidence that women have distinctive concerns about cognitive impairment. Women with a certain gene used in making protein (APOE4) are in greater danger of dementia than men with the same gene.

Some Women Face Greater Risk than Others

Inequities involving Alzheimer's and other dementias go far beyond women and men alone. Looked at through a racial and cultural lens, certain population groups are more likely to live with dementia than others.

Older African Americans are twice as likely to have dementia as older whites. Older Hispanics also have an elevated risk – about 1.5 times that of whites.²³

Little if any research has been done to explain these differences. But access to health care stands out as a possible cause. Certain physical conditions are believed to increase dementia risk, including heart disease, stress, hypertension, diabetes,

obesity, hearing loss, gum inflammation and under- or overactive thyroid activity – many of which are found in disproportionate numbers in the African American community.

Yet critical resources are often out of reach, including health care, transportation, nutritious food and safe facilities for recreation. Lower-income households struggle to pay for, or even find, long-term care.

An effective national response to the challenge of dementia must address these barriers that harm all underserved communities, including those of color. We must seek progress that is shared by all.

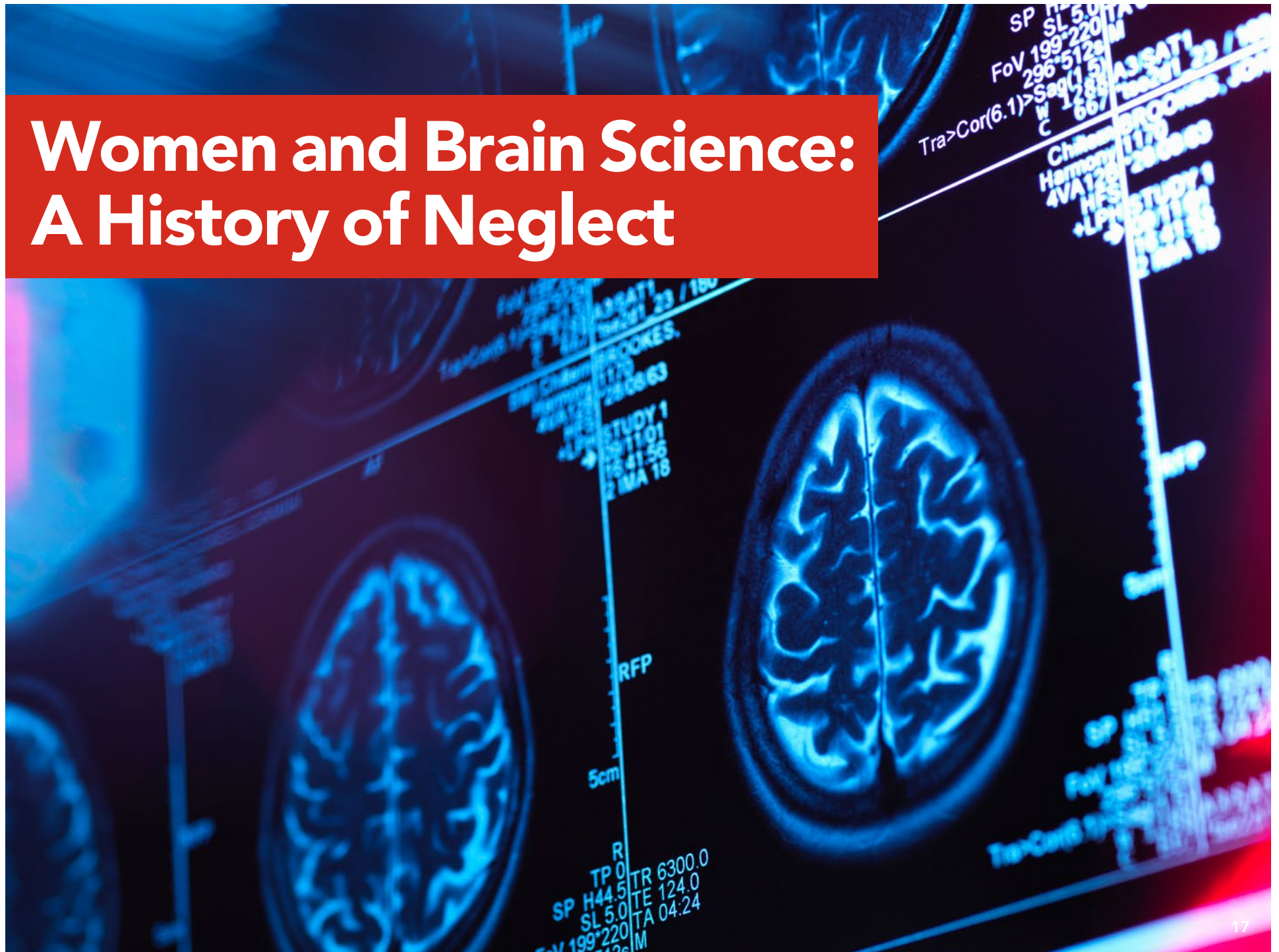
Lesson from the Heart: Gender Disparities Can be Reduced

Gender-based disparities in medical research and treatment are not unique to dementia. Women have long faced unnecessarily high death rates from heart disease. Too often they would show up at the doctor in need of critical care – only to be sent home.

But once this problem finally got national attention, treatment began to improve. Scientists belatedly found significant differences in the nature of heart disease for women and men. In the late 1990s, educational initiatives led to a great increase in public awareness, and women's deaths

from cardiovascular disease ultimately plunged by half.²⁴ Yet the problem has not disappeared. Many women are still misdiagnosed when they complain of heart problems, which may present different kinds of discomfort than what men typically describe.²⁵ Still, the lesson for dementia is clear: Greater awareness and education about gender differences can pay off greatly, leading to better treatment for women and a higher quality of life for all who live with this challenge. The push to reduce disparities must be steadfast and long term.

Women and Brain Science: A History of Neglect



“If you look at the brain scans of men and women in midlife – say their 40s through their 60s – the women show more plaque, more brain atrophy, reduced connectivity and reduced glucose metabolism. We should not think of dementia as a disease that starts in old age.”

DR. LISA MOSCONI

DIRECTOR OF WOMEN'S BRAIN INITIATIVE, WEILL CORNELL MEDICAL COLLEGE



Women have historically played little role in clinical trials aimed at learning about dementia. Until recently, the scientific research largely ignored gender-related differences. Women of color were overlooked altogether, whether because of institutional neglect, a distrust of clinical trials among many communities or some combination.

The result has been a dearth of data and a setback to public health. Much of the knowledge about dementia short-changes women. Important subgroups have been largely ignored. Too little is known about how women respond differently than men to medications, treatments or medical protocols.

New, gender-based research is needed into biology, behavior and how varied risk factors may interact. Some risks, such as depression and anxiety, affect both sexes but may be more common in women. Others, such as a decline in estrogen at midlife, or the long-term

impact of pregnancy apply to women alone. Some genes that are linked to Alzheimer's are more common in women, and some are more common in men.

Filling in the blanks for so complex an issue will require scientists to follow women and men of all backgrounds in clinical trials for many years.

Getting the Answers: Next Steps for Science

More than ever, researchers are learning that Alzheimer's and other dementias may be caused by many factors acting in confluence with one another. For women who have irregular reproductive cycles, that may be especially true. Many questions still need to be explored. But after years of neglect, more is starting to be learned.

Some of the areas of women's biology now getting the most attention from researchers:

“This is not like Zika or HIV. There seem to be multiple pathways of getting it, and there will probably be multiple pathways of addressing it.”

DR. MARIE A. BERNARD

DEPUTY DIRECTOR OF THE NATIONAL INSTITUTE ON AGING AT THE NATIONAL INSTITUTES OF HEALTH



Hormones. A decline in estrogen around menopause prompts a change in the source of energy used by women’s brains, and appears to heighten the risk of dementia.

Genetics. The gene APOE4, which helps transport fat into the bloodstream, may be a particular danger for women who have it. While recent evidence has been mixed, researchers who focused only on men and women between ages 65 and 75 found that women with that gene in that age group had a higher incidence of dementia.²⁶ Perhaps 20 other genes may bear a relationship to risk for dementia.

The Female Brain. Abnormal tau protein has been found to spread more easily and widely in women’s brains, creating harmful tangles that are linked to dementia. This was documented in a study of men and women with mild cognitive impairment, by researchers at Vanderbilt University Medical Center.²⁷

Reproductive Systems. A woman’s history of pregnancy and childbearing has emerged as an important area for research. The more time spent pregnant, and the higher number of children, may reduce a woman’s risk of dementia. But the findings diverge: Some research has found that having five or more children *increases* the risk.²⁸

In 2018, researchers at Kaiser Permanente and UC Davis found that women who had at least three children had a 12 percent lower risk of dementia than women who had one child. Women who had miscarriages had greater risk than those who did not (and rates increased with each miscarriage). Women who had their first menstrual period at 16 or later also were found to be at higher risk for dementia later in life.²⁹

Research also suggests that women who have hysterectomies may face increased chances of memory loss and dementia.

10 Questions for Scientists to Explore

Women's risks for dementia prompt many questions – in areas varied as biological, genetic and personal behavior. Factors unique to women, such as their hormonal systems, may yield vital clues to dementia's causes and pathways. Much more must be learned about why certain population groups, such as women of color, have higher rates of dementia.

Here is a partial list of 10 areas that researchers should explore further to gain further insights into gender-based differences in dementia and ultimately achieve a cure for everyone.³⁰

1.

Detection

Are early signs of dementia overlooked in women, and if so why? Research suggests the answer is yes, in some cases because stigma and fear may prevent seeking a diagnosis, and in others, because women's better verbal fluency can hide emerging memory problems.

2.

Genetics

Is the APOE4 gene more harmful for women, and if so, are certain age groups more affected than others?

More needs to be learned about genetic risks, how these may differ based on ancestry, and how environmental factors may turn genes on and off.

3.

Structure of women's brains

In what ways do they age differently from men's brains, and how does that affect women's vulnerability to Alzheimer's and other dementias? When plaque is formed, why is it less likely to be cleared out of women's brains than men's?

4.

Course of disease

Does dementia progress more rapidly in women, as some of the research suggests?

5.

Reactions to treatment

As treatments are tested in clinical trials, how do men and women respond differently?

6.

Women's reproductive systems

How do such factors as the age of first menstruation, number of pregnancies,

childbirth and miscarriages affect the odds that a woman will get dementia?

7.

Hormones and menopause

What are the specific connections between perimenopause, menopause and dementia risk? Is a menopause-induced disruption in sleep a factor?

8.

Hormones and therapy

Can research on midlife changes in estrogen pave the way to hormone treatments to prevent or ease dementia?

9.

Chronic illness

How do heart disease and other chronic conditions affect the risk for dementia, and what are the differences between men and women?

10.

Inflammation

What is the connection between inflammation and Alzheimer's/dementia?



Beyond Biology: Factors Influencing Brain Health

“Women are more likely to pick up the financial burden for care. They are less likely to have financial resilience through their course of life.”

FIONA CARRAGHER

CHIEF POLICY AND RESEARCH OFFICER, THE ALZHEIMER'S SOCIETY



Just as we are learning more about the importance of women's biology in influencing brain health, we are recognizing that other factors also play a role. Differences in emotional well-being, lifestyle priorities and approach to wellness all may influence cognitive abilities later in life.

As researchers try to unravel the mysteries, they are homing in on an array of behavioral and societal influences that may make some women more vulnerable than others:

Depression. Being depressed in midlife has been found to elevate the risk of Alzheimer's for men and women – but women are twice as likely to become clinically depressed.³¹

Stress. The pressures of modern life may take a special toll on women, who report high levels of stress as they juggle careers and family obligations. Ongoing stress and anxiety can depress the immune system, cause depression and increase the risk

of Alzheimer's.³² Stress levels are also high in low-income communities, which also have higher levels of risk.

Exercise. Frequent exercise has been found to be one of the most constructive steps a person can take to preserve their brain health, and studies have consistently found that women exercise less than men.³³

Diet. Unhealthy eating habits can undermine brain health yet are widespread in the United States. Saturated fats, such as those found in fatty meats and dairy foods, including ice cream, are among the culprits that many people consume frequently.

Work. Specifically, work outside the home. UCLA researchers have found a faster rate of cognitive decline in women who never worked outside their own home when compared to women who did.³⁴

Beyond the Individual: How Society Affects the Brain's Well-Being

Think about it: Where you grow up can affect everything from the quality of your schools to your access to health care to your career aspirations. Coming to grips with dementia and women requires a critical look at how society influences brain health over a woman's lifetime.

Social policy, economic factors and supportive services can all affect a woman's life experience – and cognitive health – in consequential ways.

Education. Research suggests that higher levels of education may reduce dementia risk, and women's educational attainment has actually surpassed that of men in the United States. But lack of education may still pose risk for many, including low-income African Americans and Hispanics.

Services. Livable community environments that promote access to supportive services, social engagement and recreation should be encouraged as a way to promote well-being in older adults.



Opportunity. Good jobs, in which people must use their brains, have been linked to better brain health in later years.

Nutrition. Throughout the world, poverty has been shown to harm the development of children, with long-term effects³⁵ on their brain health. Residents of neighborhoods with little access to wholesome food may find it harder to maintain nutritious diets that are needed for healthy living.^{36 37}

“We must increase culturally sensitive recruitment and retention efforts to expand the participation of women and communities of color through tailored awareness and engagement. We need to explore strategies to bring clinical trials into underrepresented communities, including the utilization of mobile testing sites.”



NORA SUPER

SENIOR DIRECTOR, CENTER FOR THE FUTURE OF AGING, MILKEN INSTITUTE

Underserved Communities Require Attention

The life-affirming supports that encourage wellness and brain health are frequently lacking in low-income areas, and underserved communities, often of color, experience higher rates of cognitive decline in their later years.

Although research has been inadequate, scientists are slowly building a knowledge base to explain why dementia is more prevalent in some communities than others:

Where you live matters for the brain. Research has shown³⁸ that people born in the “Stroke Belt” in the southern United States had a 28 percent higher risk of dementia than those born elsewhere. Importantly, birth in a high stroke mortality state was approximately 10 times more likely for African Americans than whites, and dementia risk was correspondingly high for blacks born

Can Sex-Change Operations Yield Clues About Brain Health?

Some experts believe that radical changes in hormones, such as in sex-change procedures, provide an opportunity to gain insight into the impact of hormones on cognitive health. In switching from male to female, estrogen is increased. In switching from female to male, estrogen is suppressed. Different medical procedures, such as cancer treatments, may also entail radical hormone shifts. Such changes can provide new insights into the long-term effect of hormonal changes on the brain. Science has shown that the removal of even one ovary may heighten the risk of dementia later in life. More research is needed.

in those regions relative to whites. The region studied is known for high rates of diabetes and high blood pressure.

Childhood education strengthens resistance to dementia. A National Institutes of Health (NIH) study of African Americans in Indianapolis found that more years of schooling reduced the likelihood of dementia later in life for those who had grown up in rural areas.³⁹ The findings were not matched for African Americans who grew up in urban neighborhoods, suggesting that additional factors, such as local economic conditions and resources, may affect dementia risk.

Genetic risks differ based on ancestry. One NIH study found that African Americans with a gene variant known as ABCA7 have a substantially higher risk of dementia.⁴⁰ A study of Hispanics highlighted the genetic diversity within the Hispanic population, including differences in genetic risk factors based on specific ancestry.⁴¹

Such findings show that we must improve outreach to communities of color and different ethnicities and make sure they are sufficiently included in clinical trials. Studies based on whites alone are inadequate to explain the complex and varied pathways of Alzheimer's and other dementias in a diverse society.



Yet communities with a disproportionate amount of dementia are still underrepresented in federally funded research. Just 2 percent of participants in studies of drugs to treat brain plaque were African American, according to the Milken Institute, even though 20 percent of individuals with Alzheimer's are African American.⁴² Women of color, notably African Americans and Hispanics, need significantly more representation in clinical trials – a task made more difficult by a legacy of racism in science.



Caregivers: Most are Women and Pay a Price

“Stigma is a huge problem because so much is at stake with a dementia diagnosis. People are afraid to discuss brain health with family members. People are afraid to mention it to their care providers. People are afraid of losing their independence, losing their status, losing their jobs.”

REV. DR. CYNTHIA HULING HUMMEL
ADVOCATE/ARTIST/AUTHOR



More than six out of 10 Alzheimer’s caregivers are women.⁴³ Their acts of devotion are invaluable to loved ones with dementia, who may also be doing all they can for themselves in a partnership of care. Too often, however, caregivers have insufficient support and guidance for efforts that may be required seven days a week.

Research suggests that women caregivers do more for patients than male caregivers. Twice as many female caregivers live fulltime with the person they are helping than male caregivers do.⁴⁴

Dementia caregivers may have to navigate around their loved one’s confusion and mood swings, which may worsen over time. Adding to the stress, a caregiver may feel torn between caregiving and other commitments, including to family members.

The Sandwich Generation and Millennial caregivers

Who provides all that essential care? The “typical” caregiver is a woman in midlife who may be a member of the Sandwich Generation, caring for older parents while still raising her own kids. But a new generation of caregivers is emerging.

About one in four caregivers is now a Millennial.⁴⁵ Most Millennial caregivers are employed outside the home, and more than half are African American, Hispanic or Asian/Pacific Islander, many of modest means.⁴⁶ The need to juggle work and caregiving may reduce their income, limit their options to buy homes, and reduce education options for their children or themselves.

The Cost in Caregivers’ Health

Inevitably, many caregivers sacrifice their own health. Anxiety, depression, substance abuse and chronic illness have all been linked

“This pandemic is a perfect storm for women and dementia. Physical distancing has increased social isolation, which is linked to a 50% greater risk of dementia. Yet now women have even fewer financial resources to cope with these challenges, given pandemic-related loss of jobs and health care benefits.”



LISA MARSH RYERSON
PRESIDENT, AARP FOUNDATION

to caregiving,⁴⁸ including dementia. Family caregivers have higher risk of heart disease, lower levels of self-care, and higher rates of death.⁴⁹

One study found that over 18 months, female dementia caregivers had twice the rate of emergency room visits and other hospital services than non-dementia family caregivers.⁵⁰ Another study found that dementia caregivers may face a higher risk of cognitive decline.⁵¹

The societal and human costs of social isolation have been brought to the forefront during the COVID-19 crisis. With loneliness now recognized as a contributor to long-term health care issues, from cardiovascular disease to depression, we cannot ignore the effect of loneliness and isolation on caregivers' health. One study (pre-coronavirus) found that isolation drives up Medicare costs by almost \$7 billion a year.⁵²

The Cost in Financial Security

A 2016 AARP study found that caregivers overall spent nearly 20% of their income on those they care for, and dementia caregivers paid the most – \$10,697 a year in out-of-pocket costs compared to \$5,785 for loved ones with other conditions.⁵³

Family caregivers who also have paying jobs can face tremendous pressure. They may feel compelled to cut corners at work and take days off, which can hurt their careers and lead to lower pay. In the course of a lifetime, such career disruptions may lead to smaller nest eggs, lower retirement benefits and less financial security in old age.

The sacrifice may be greatest for low-income families of color. White caregivers (for all diseases) spent 14 percent of their income on household, medical and other expenditures for loved ones they were helping, according to the 2016 AARP study. African Americans spent 34 percent, and Hispanics spent 44 percent.



The Path Forward: Achieving Equality in Brain Health

“There’s a feeling that if I’m going to get it (dementia), I’m going to get it, and there’s nothing I can do about it. That’s wrong. We need greater public understanding that it’s not inevitable, and people can do a lot of things to reduce their risk.”

LYNN POSLUNS

FOUNDER OF THE WOMEN’S BRAIN HEALTH INITIATIVE

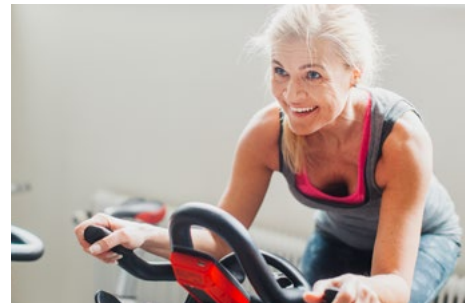


The roadmap for significant and lasting change calls for action on many fronts, including social policy, public awareness, access to quality health care, and support for caregiving responsibilities in all communities.

Women can take important steps to help themselves. But solutions will also require a broader societal effort, with important roles for employers, policymakers, scientists, health care professionals and faith-based institutions.

- Prevention will make life better for millions. Much more can be done to protect women’s brains and prevent dementia before it emerges.
- Mitigation strategies will help individuals and families. Prevention is ideal, but better mitigation remains vital for a problem that does not yet have a cure.

What follows is a series of solutions that society can pursue to achieve equity for women in brain health – and a strategic plan to get us there.



Raising Awareness Among Women

Problem: *Women may not realize the steps they can take to stay sharp and help prevent dementia in their later years.*

Solution: *Empowering women with the facts and information they need to protect their brain health.*

Experts agree that eating right and staying physically fit can help protect brain health. For example, the prestigious [Lancet Commission on Dementia Prevention, Intervention and Care](#) found that taking such steps could “transform the future” for families, and that more than one-third of dementia cases globally might be prevented by addressing lifestyle factors.⁵⁴

Yet women get less exercise than men. Research has shown that women’s levels of exercise drop off substantially after high school, and the decline may be worst for women of color.⁵⁵ Adding to the concern, the number of out-of-shape women may be rising.⁵⁶

Much of the guidance on healthy living applies to men and women, such as the benefits of a good night’s sleep, not smoking, drinking only moderately and staying socially engaged. Managing health care conditions is also an important personal strategy, such as controlling for vascular risks, including high blood pressure, high cholesterol and diabetes.^{57 58 59}

Yet changes in social behavior, once associated mainly with men, are now affecting more women, such as smoking, drinking to excess and drug abuse.⁶⁰ It is important that women recognize the consequences of unhealthy actions – and the importance of reserving time to take care of themselves.

For more details on steps you can take to protect brain health, including nutrition and sleep, go to: <https://www.aarp.org/health/brain-health/global-council-on-brain-health/>.



Stress and Anxiety

Problem: *Modern life contributes to stress and other challenges that undermine women’s mental well-being.*

Solution: *Difficult as it may be, women must do all they can to manage stress and get the care they need to stay mentally healthy.*

Unfortunately, stress is a dementia risk, yet it is a fact of life for many women.⁶¹

Pressures that contribute to women’s stress include participating in the paid workforce while also struggling to support families at home and providing care for ailing loved ones. This is a particular issue for the Sandwich Generation, which takes in Boomers, Xers and Millennials.

These pressures can be intense: Women may have twice the levels of extreme stress and anxiety as men.⁶²

Isolation is another problem experienced by many women, including those who are widowed, divorced or never married. Experts tell us

that loneliness and isolation also may be linked to declines in brain health and the risk of dementia.

The answer is for women to do what they can to strengthen and preserve their mental well-being. Staying connected to people they care about and staying engaged in worthwhile activities can support a sense of purpose and inner peace that help protect their brains.



Gaps in the Research

Problem: *Researchers have neglected the brain-health issues of women and people of color, resulting in limited understanding of dementia's many pathways.*

Solution: *Scientists and government funding agencies must take a more inclusive approach that ensures the engagement and input of all communities in formulating and conducting research on the brain.*

Women's participation in dementia research has significantly improved – women now make up more than half the subjects in clinical trials on Alzheimer's disease funded by NIH.⁶³ NIH's *Inclusion Across the Lifespan* policy now requires researchers to report data on age, sex and race/ethnicity. Despite the progress, however, brain-health research must go much further to reflect the whole population.

Participation in clinical trials by African Americans and Hispanics remains meager and insufficient. Much stronger, culturally sensitive efforts are required to recruit diverse participants for clinical trials. This may call for outside-the-box thinking, such as mobile testing sites to attract participation from communities that do not trust federal research.

More broadly, the entire culture of research should elevate diversity as a priority. Such awareness should be built into questions for study and analysis of the data. This goal would be furthered if the scientific community itself were more diverse, including more women researchers.



Juggling Work and Caregiving

Problem: *Dementia caregivers who also work outside the home face burnout, financial sacrifice and a lack of support.*

Solution: *Employers should adopt paid leave, health care benefits, flexible work schedules and other policies that support caregiving.*

According to the Alzheimer’s Association, nearly 19% of dementia caregivers end up quitting their paid jobs to provide care.⁶⁵ By remaining flexible, employers make it easier for their workers to balance competing demands, and stay more productive in their paid jobs.

Whether employed or not, dementia caregivers need more support, and such needs may be most pronounced in low-income communities. More support services, backed up by community outreach⁶⁶ and culturally sensitive education, can ease stress on caregivers. The dementia workforce, including health care clinicians and paid caregivers, should be trained to become more culturally competent to serve diverse populations.

Individuals with dementia and their caregivers would benefit greatly from “dementia navigators” who could guide them through the maze of support services and medical appointments.



What the Public Doesn’t Know

Problem: *There remains a lack of public awareness that women, especially women of color, face an exceptional burden for dementia.*

Solution: *A national effort of consumer education, involving the public and private sectors, can help people understand the challenge and the steps they should take.*

Most Americans are not aware that women face an increased risk for dementia, according to a survey by the Women’s Alzheimer’s Movement.⁶⁷ Just 17 percent of adults recognize the greater incidence among women.

Improved public education can address the stigma of dementia. It can encourage conversations within families and with doctors. And it can clarify that individuals in early stages retain much more mental ability

than in later, advanced stages. Only one-third of adults said they have discussed brain health with their doctors. Anecdotally, many believe that dementia is an inevitable part of aging rather than the result of a condition such as Alzheimer's.

Useful Information Should be Crafted with Specific Audiences in Mind:

Younger women. It is important for them to know that brain changes may start to occur in midlife – many years before obvious symptoms of cognitive impairment. This knowledge may encourage more women to behave in ways that support their brain health.

Workers. Employer handbooks that educate workers on measures to support brain health and prevent dementia could have tremendous impact on women, who may not know they are at higher risk. Private and public health plans should build in incentives for encouraging lifestyle adaptations that lead to better health, including brain health.

Underserved communities. Culturally sensitive messaging about brain health, dementia causes and local resources can be of value to population groups at greatest risk, including African Americans and Hispanics. Hispanics and African Americans have above-average rates of heart disease and diabetes, which heighten the risk of dementia – information they need to know.⁶⁸

Trusted professionals. Investment advisors and others in financial services are among the professionals who may be the first to

notice impaired cognition by consumers. They should be trained to notice warning signs and have protocols for helping consumers when such situations present themselves. Others who deal with the general public, including mail carriers, police, firefighters and paramedics, also need such training.

A Strategic Plan to Conquer the Problem

Although the road to equality may be uphill, we see a path forward that will benefit families all over the world. Too much time has passed since the Women's Alzheimer's Movement first called attention to the inequities that dementia poses for women. Society must now take the sweeping actions needed to address this issue.

Fundamental to improving brain health and reducing risk for Alzheimer's and dementia for all people – regardless of sex, race or economic situation – is to address inequalities across society. Access to quality health care can ease chronic health conditions that predispose people to cognitive impairments. Decreasing inequities in the social determinants of health such as education and environmental exposures will pay off for all people. We have identified five key issues particularly relevant to women, due to structural gender inequalities and expectations.

What follows is a 5-point Strategic Plan for real progress over the next decade. Through collective action focused on these crucial priorities, we believe we can achieve significant change for women before 2030.

Working together, we can:

5-point Strategic Plan



1. Eliminate the stigma of dementia

All of society must recognize dementia as a public health problem for which women pay an exceptional price. It is not a normal feature of aging, yet stigma often stands in the way of early detection and early interventions. We all have a role to play in fixing this inequity, including policymakers, researchers, health care providers and individuals.



2. Empower women to promote their own brain health

A growing body of research suggests that a healthy lifestyle – based on good nutrition, lots of exercise, and careful management of health conditions – can cut the risk of dementia by more than a third. Women should be encouraged to act on this hopeful and empowering information and recognize that as the majority of family caregivers, females often ignore their own well-being at their peril.



3. Invest in research that is inclusive

We need to learn more about the causes of Alzheimer's and dementia in all women. Scientists must accelerate efforts to understand sex-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. Researchers must learn why dementia affects so many women and underserved communities, and such data should be highlighted in their findings.



4. Enhance support for family caregivers

All family caregivers should have access to training and support for care for people living with dementia including respite that can give them a much-needed break. Employers should provide paid leave for employees who provide care at home. Finally, caregivers need access to affordable health care coverage for themselves and their loved ones whether employed outside the home or not.



5. Improve training for care providers

Health care providers should better recognize cognitive decline in older women. Doctors also should be taught to discuss dementia concerns with sensitivity and compassion. Evidence-based, person-centered care should entail proactive steps to optimize quality of life for all who live with dementia. A team-based approach across all health and social care professions will abolish the outdated notion there is nothing you can do about dementia.



When AARP and the Women’s Alzheimer’s Movement joined forces to sponsor the brainstorming session in 2019, our goal was to inspire a powerful new wave of collaboration to enhance brain health for all. We are committed to developing actionable steps toward a cure for dementia, driven by research that is sensitive to gender differences, greater public awareness and the need for inclusive, equitable solutions.

Women belong in the forefront of this mission, because they have the most at stake in the battle against dementia.

This report is a call for women to take ownership of their brain health, not only for themselves but for those they care for. We urge women to help lead the way to meaningful progress that will benefit all of society. Doing so will improve the lives of women and men throughout the world – not just today but for generations yet to come.

Endnotes

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Resources

Additional resources related to women and brain health (submitted by collaborators)

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FACTSHEET

MARCH 2020

alzimpact.org

Women and Alzheimer's Disease

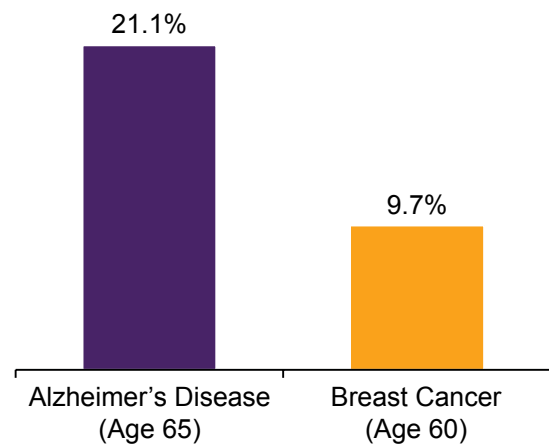
Women are at the epicenter of the Alzheimer's crisis. Almost two-thirds of American seniors living with Alzheimer's disease are women.

- An estimated 3.6 million women aged 65 and older are living with Alzheimer's.
- Among those aged 71 and older, 16% of women have Alzheimer's and other dementias, compared with 11% of men.
- At age 65, women without Alzheimer's have more than a 1 in 5 chance of developing Alzheimer's during the remainder of their lives, compared with a 1 in 9 chance for men.
- 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.

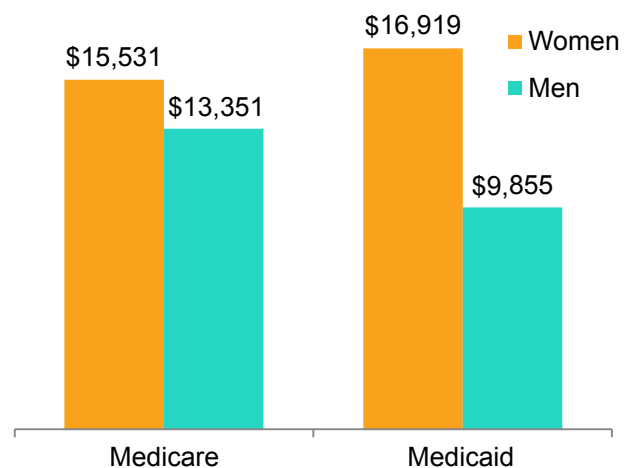
Individuals with Alzheimer's have higher health care costs. But, women with the disease have higher costs than men.

- Over the course of a lifetime, a woman with Alzheimer's will cost Medicare, on average, \$15,531 more than a woman without Alzheimer's. This is 16% higher than the "incremental cost" for men with the disease.
- Under Medicaid, a woman with Alzheimer's will have \$16,919 more in costs than a woman without — more than 70% higher than the incremental costs for male Alzheimer's patients.

Remaining Lifetime Risk of Women Developing Alzheimer's Disease and Breast Cancer



Average Lifetime Costs of a Person with Alzheimer's In Excess of a Person Without Alzheimer's



Not only are women more likely to have Alzheimer's, they are also more likely to be caregivers of those with Alzheimer's.

- Studies have consistently shown that women make up 60% to 70% of all unpaid Alzheimer's and dementia caregivers.
- This means that as many as 11 million women are currently providing unpaid care to someone with Alzheimer's or another dementia.

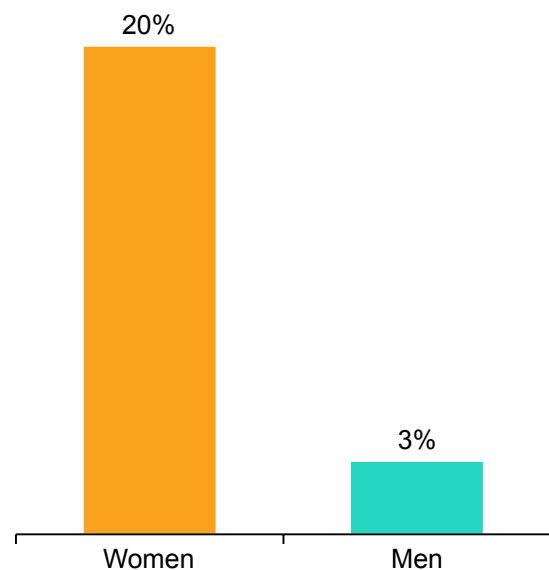
Women caregivers provide more intense care for longer periods of time.

- There are 2.5 times more women than men who provide on-duty care 24-hours a day for someone with Alzheimer's.
- Similarly, there are 1.7 times more women than men who have been providing care to someone with Alzheimer's for more than five years.
- Studies show female caregivers take on more caregiving tasks than their male counterparts — and care for people with more cognitive, functional, and/or behavioral problems.

Caregiving responsibilities take a toll on women's health and well-being.

- Almost half of all women Alzheimer's caregivers say caregiving is physically stressful. This is twice the rate as male Alzheimer's caregivers.
- While about one-third of both men and women Alzheimer's caregivers feel isolated as a result of their caregiving duties, for women, this feeling is much more commonly linked to depression.
- Nearly three-quarters of women caregivers express concern about the ability to maintain their own health since becoming a caregiver.

Percentage of Working Alzheimer's Caregivers Who Have Gone from Full-Time to Part-Time Work



Because of caregiving duties, women are likely to experience adverse consequences in the workplace.

- Nearly 19% of women Alzheimer's caregivers had to quit work either to become a caregiver in the first place or because their caregiving duties became too burdensome.
- Among working women caregivers, 20% have gone from working full time to part time, compared with only 3% of working male caregivers.
- Other employment effects on working women caregivers include:
 - 18% have taken a leave of absence from work
 - 10% have lost job benefits
 - 17% felt they had been penalized at work because of their caregiving duties.