



# The Campaign for Women's Brain Health A Catalyst for Change

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## What Women Are Saying

- Most women are concerned about brain health, but few currently discuss it.
- Nearly **70%** of women surveyed express interest in learning more about ways to measure and track brain health.
- Nearly **90%** of women agree that taking care of their brain is just as important as the other parts of their body.
- More than **80%** of women say we should be talking about brain health more.

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## Empowering Women to Transform Brain Health

With a rapidly aging global population, the staggering number of people with cognitive decline, and a complex path to curing Alzheimer's and related dementias, the importance of focusing on brain health is clear. Women—as the Chief Medical Officers of families across racial, ethnic, and socio-economic boundaries—have a unique opportunity to take the lead in a nationwide brain health movement. In order to understand more about women's perceptions, attitudes, and willingness to lead, we conducted original research, presented here, that reveals important opportunities to change attitudes and behavior with women in the lead. Women are ready to take action on their own brains and to lead their families and communities to better brain health.

Our research shows that women see brain health as a top health priority and want to learn, discuss, and do more. That's why we're launching Be Brain Powerful, the Campaign for Women's Brain Health: a nationwide movement joining women to transform brain health in their families and communities. Women have already been change-makers for the key health issues of our time, from heart disease to breast cancer. By empowering women with the tools to lead, we can change the trajectory of brain health for ourselves, for our families and communities, and for future generations.

This Campaign is one pillar of the new Brain Health Partnership from UsAgainstAlzheimer's (UsA2), supported by the Alzheimer's Drug Discovery Foundation, the Vrandenburg Foundation, and many other private sector and non-profit leaders.

The Brain Health Partnership is a new multi-pronged, multi-year initiative to ensure our society, healthcare system, and policymakers treat brain health as an integral element of overall good health and identify cognitive decline early.

## **The Urgent Challenge of Alzheimer's and Related Dementias (ARD)**

Alzheimer's and related dementias present one of the greatest health, social, and economic challenges facing women, in the United States and globally. Already, 5.7 million Americans are living with the disease, at a national cost of more than \$275 billion.<sup>1</sup> Two-thirds of those affected are women, and women shoulder nearly 80% of the disease's total economic burden.<sup>2</sup> Women also account for two-thirds of the 16.1 million family caregivers who provide more than 18 billion hours of unpaid care each year—valued at \$232 billion.<sup>3</sup> This burden falls disproportionately on African American and Latino women, as African Americans are roughly twice as likely to have Alzheimer's and related dementias as whites, and Latinos are 1.5 times as likely.<sup>4</sup>

As the population ages, the impact of Alzheimer's threatens to devastate families, communities, Medicare and Medicaid, and the U.S. economy. By 2050, prevalence is projected to soar to nearly 14 million, and costs are set to rise to more than \$1 trillion.<sup>5</sup> This would mean millions of people living and dying with this terrible disease, tens of millions more struggling to provide care, and soaring costs that are fiscally unsustainable for the U.S. healthcare system and economy.

Currently, neither everyday Americans, nor our healthcare system are prepared for the scale and speed of the Alzheimer's crisis. Providers struggle to proactively address brain health with their patients, and those patients refrain from asking due to fear and stigma. For example, research has found that health care providers do not disclose an Alzheimer's

diagnosis to the majority of the people with the disease; much less proactively address brain health with all patients.<sup>6</sup> In research conducted in 2016 in the women's health space, just 18% of nurse practitioners working in women's health reported that they often raise the issue of memory and brain health, and nearly 30% never raise the issue.<sup>7</sup>

Rates of early detection and diagnosis are low across the board: the estimated number of people over 65 with any cognitive impairment is between 25% and 40%, but 60% to 80% of these cases go unrecognized.<sup>8</sup> Late and inaccurate diagnosis, in turn, slows progress towards a cure, as 85-90% of Alzheimer's trials have significant trouble recruiting on schedule, and only 7% recruit the projected number of participants.<sup>9</sup> Clinical trials also struggle to recruit from minority communities, as African Americans account for just 3-5% of trial participants, and Latinos account for just 1.5%.<sup>10</sup>

We must act now. If we unite key stakeholder groups to transform brain health, we can address the impacts of the disease, push towards treatment breakthroughs, and ultimately develop a cure.

## **Our Solution: Uniting for Meaningful Change**

We see a vital opportunity to build a women-led public health movement on brain health, as a pillar of UsA2's Brain Health Partnership. The Brain Health Partnership is a new multi-pronged, multi-year initiative that aims to broaden the fight against Alzheimer's. The Partnership offers a comprehensive strategy to bring about change by engaging three key important constituencies: families and communities; providers, payers, and health systems; and policymakers. Change won't happen overnight, but engaging women to drive change in their families and communities can be the catalyst — coordinated with the other two pillars of the Brain Health Partnership: providers, payers, and health systems; and policymakers.

Our new research has important implications for each pillar of the Partnership:

- Families and Communities:**  
**Women Lead the Way on Brain Health**  
 Women are ready to promote awareness of the information, steps, and tools needed to take control of their brain health and the brain health of their families and communities. With the Campaign for Women's Brain Health, we will alert women to the critical value of brain health, so we can reduce our risk and drive system-wide change. This will empower women, families, and communities to discuss and track brain health, proactively seek cognitive assessment and screening, and search for trial opportunities.
- Providers, Payers, and Health Systems:**  
**Support Brain Health at Every Step**  
 Providers, payers, and health systems can prioritize brain health and help people to understand it, recognizing that women want to learn more and drive change in their families and communities. These key health stakeholders can drive change by mapping an optimal brain health care plan, identifying and scaling cost-effective health systems change, leveraging technology for prevention and care, prioritizing prevention and proactive care, and improving care coordination and connections to clinical trials.
- Policymakers: Prioritize Brain Health on the Public Health Agenda**  
 Recognizing the need for action on brain health, policymakers can drive significant policy change that transforms a costly, reactive system into a cost-effective, proactive early detection and care system that clears the path to a cure. This will require that policymakers prioritize brain health on the public health agenda, develop more effective reimbursement and regulatory frameworks, advance pilot programs with the Department of Veterans Affairs, and improve

multi-stakeholder engagement and data usage. Policy action on brain health is also a fiscal and economic imperative, as \$7.9 trillion is the estimated potential cost savings if all Alzheimer's cases were diagnosed early, during the mild cognitive impairment (MCI) stage.<sup>11</sup>

A game-changing brain health movement is within reach, and our research shows that change will happen if we start with women.

### A New Path: A Coordinated Initiative with Women in the Lead on Brain Health to End Alzheimer's

Knowing the key role that families and communities will play in transforming brain health and in creating demand for the healthcare system to meet the growing need for brain health care, we commissioned research to understand how to reach women where they are and to better understand how to engage women to take the lead in consumer behavior. Here are our findings:

In 2018, we surveyed thousands of women in the U.S. about their perceptions of brain health. The research reveals that women see brain health as an important priority and want to learn more, including the steps they can take in their own lives. However, many are not currently discussing the topic and need help understanding where to begin.

### Women Want to Learn and Do More on Brain Health

Working with HealthyWomen — a leading independent, nonprofit information source for women — we first surveyed 1,001 women between the ages of 35 and 64 to understand what they know and want to learn about brain health, as part of a larger research effort. The research consisted of a 15-minute online survey, and the women surveyed were balanced to represent national demographics based on age, ethnicity and race, and geography.

The survey found that:

- **Most women are concerned about brain health, but few currently discuss it.** 64% of women worry about the health and performance of their brains as they age. Yet less than 10% of women discuss brain health regularly, and less than 50% are aware of preventive or proactive measures they can take to maintain and protect their brain health.
- **Women want to learn and do more to protect their brain health.** Nearly 70% of women surveyed express interest in learning more about ways to measure and track brain health. Two-thirds of these women said that, if it were possible, they would ask their healthcare provider to measure their brain health to protect or maintain it.
- **There is an opportunity for more women to protect their family's brain health.** Although most women agree that brain health is important for more than just older people, the majority aren't taking steps to promote their family's brain health. Only 17% of women take steps to protect the brain health of their parents, and just 30% take steps to protect the brain health of their children.

### Women Believe Brain Health Is Important and Should Be Discussed Regularly

In addition to the broad research with HealthyWomen, we conducted our own survey to drill down and understand not just whether women want to engage on brain health, but how women want to engage. Our goal was to understand the actions that women think we should be taking on brain health, as well as the barriers that may prevent them from taking these actions. The research consisted of a 15-minute online survey with a separate group of 1,350 women between the ages of 25 and 65, who were nationally representative of ethnicity.

The survey found that:

- **The vast majority of women agree that brain health is important and should be discussed more.** Nearly 90% of women agree that taking care of their brain is just as important as the other parts of their body. More than 80% say we should be talking about brain health more, and around 70% say brain health should be discussed regularly with their family and their doctor.
- **Women see brain health as a top health issue, but need information to take action.** 55% of women see brain health a top health concern—one of the highest levels for any issue—but just 35% are currently taking action. Many don't know how to begin: 45% say maintaining a healthy brain sounds important, but don't really know what that means.

### How We Can Build a Women's Brain Health Movement

Our research shows that women are ready to lead a public health movement on brain health. Together, we can focus on brain health and make sure it's discussed in every family and community. We just need to provide all women with the information and tools to drive real-world change.

We know that women have the power to transform the key health issues of our time. For example, in the 1980s, the creation of National Breast Cancer Awareness Month and organizations like The Susan G. Komen Breast Cancer Foundation fought stigma and brought awareness to a disease that impacts millions of women each year.<sup>12, 13</sup> Or consider Go Red for Women, The Heart Truth, and other women's heart health efforts, which have driven heart disease awareness and lifestyles changes for millions of women since the early 2000s.<sup>14, 15</sup> In both examples, the science came first. Prevention

and screening were well-understood. Women took that information and turned it into advocacy, resulting in greater awareness and more funding.

A women-led brain health movement will go even further. While cancer and heart disease were already understood scientifically and medically, women united for brain health will be at the forefront of breakthroughs in how we understand and treat Alzheimer's. Simply put, women will transform brain health for everyone—women and men, young and old, now and in future generations.

The Campaign for Women's Brain Health will join women to achieve this vision, as a pillar of UsA2's Brain Health Partnership. Please join us in this important new effort.

## Endnotes

- 1 <https://www.alz.org/alzheimers-dementia/facts-figures>
- 2 <https://assets1b.milkeninstitute.org/assets/Publication/ResearchReport/PDF/dementia-v5.pdf>
- 3 <https://www.alz.org/alzheimers-dementia/facts-figures>
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- 11 <https://www.alz.org/alzheimers-dementia/facts-figures>
- 12 <https://www.nationalbreastcancer.org/about-nbcf/nbcf-story>
- 13 [https://ww5.komen.org/ourimpact/?utm\\_source=Komen.org&utm\\_medium=GlobalHeaderCTA&utm\\_campaign=OurImpact](https://ww5.komen.org/ourimpact/?utm_source=Komen.org&utm_medium=GlobalHeaderCTA&utm_campaign=OurImpact)
- 14 <https://www.goredforwomen.org/fight-heart-disease-women-go-red-women-official-site/about-go-red/>
- 15 <https://www.nhlbi.nih.gov/health/educational/hearttruth/about/index.htm>