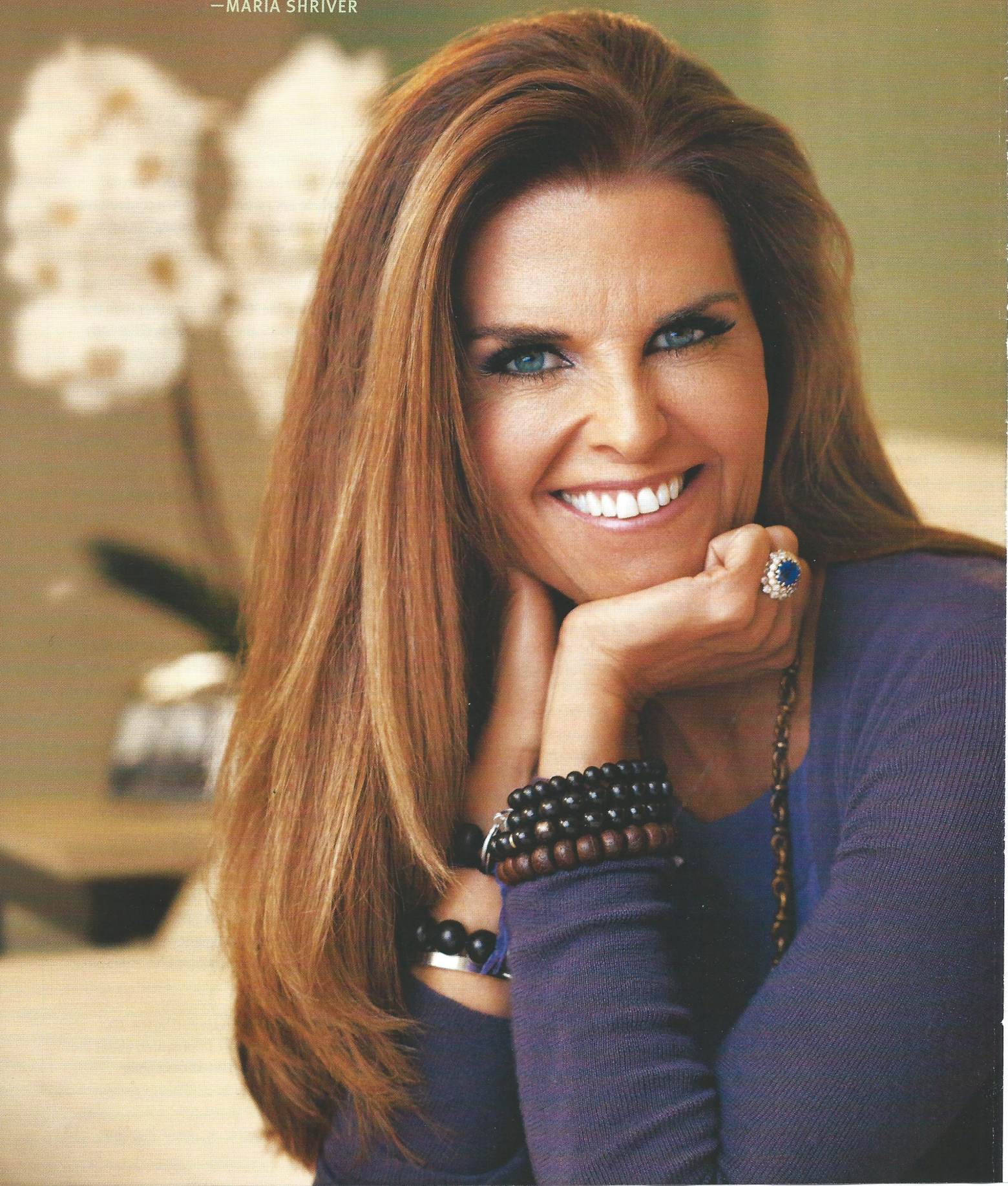


“No one could answer my questions, like ‘Why is this happening?’ and ‘What **can be done** to address the changes Alzheimer’s brings?’”

—MARIA SHRIVER



Conversation Starter

After her father's diagnosis, Maria Shriver started talking about Alzheimer's disease. Ten years later, she's still talking, and people are beginning to pay attention.

BY GINA ROBERTS-GREY

In 2003, Maria Shriver's father, Sargent, was diagnosed with Alzheimer's disease. Over the next decade, Shriver watched her once articulate, witty, whip-smart father—founding director of the Peace Corps, part of the Kennedy and Johnson administrations, director of various War on Poverty programs, head of the Special Olympics, recipient of the Presidential Medal of Freedom—descend into dementia. In the later stages of the disease, she had to introduce herself to him when she came to visit—a recollection, she says, that still makes her cry.

As a news journalist, Shriver was used to asking questions, getting answers, and sharing that information with others. Within a year of her father's diagnosis, she was bringing those skills to bear on Alzheimer's disease. "I didn't know that much about Alzheimer's," she admits, "and no one could answer my questions, like 'Why is this happening?' and 'What can be done to address the changes Alzheimer's brings?'" To find the answers, she sought out doctors, researchers, and other families dealing with the disease. She wanted to know where the research was headed, how doctors treated the disease, and how families coped. She was personally familiar with the shame and embarrassment associated with the disease, and her experience was corroborated by others. She also knew that Alzheimer's disease affects entire families, from spouses and partners to children and grandchildren.

PUBLIC DISCOURSE

The more she learned, the more she realized she wanted to start a national conversation, one she hoped would translate into more support for people with Alzheimer's disease and their families, more funds for research, and more attention from public officials. Her conversation opener was *What's Happening to Grandpa?*, a children's book she wrote in 2004 that explained Alzheimer's disease to kids. It also offered ways

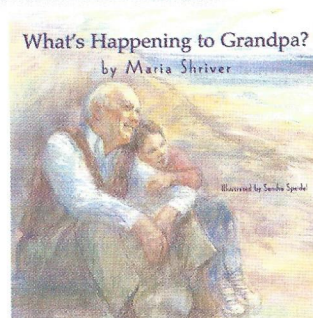
for children to interact with an older person with dementia. Shriver donated copies of the book to the Alzheimer's Association, whose mission has been supported through sales of the book.

Shriver says the book came out of conversations she had with her four children, who asked many questions as their grandfather declined. In the book, she tries to answer those questions.

Four years later, Shriver took her cause public when she testified in front of the US Senate Special Committee on Aging. Calling herself "a child of Alzheimer's," she reminded committee members of her father's intellect before his diagnosis, saying his mind was "a beautifully tuned instrument that left people in awe and inspired." She urged Congress to invest more money in finding drugs to treat or prevent Alzheimer's disease.



DADDY'S GIRL Maria Shriver with her dad, Sargent (above), in 2007, three years after he was diagnosed with Alzheimer's disease; *What's Happening to Grandpa?*, the book she wrote in 2004 to help explain the disease to children.



“Let your federal and local elected officials know that this is a priority, that the **cognitive health of women** is a serious matter worth fighting for.”

—MARIA SHRIVER

RAISING AWARENESS AND FUNDS

That same year, Shriver produced an HBO special called *The Alzheimer's Project*. The series of four documentaries and 15 supplemental films look at the science and research and how children are affected by the disease and includes stories from patients and their caregivers. With every project, Shriver says she seeks to demystify the disease, to take it out of the shadows, and to shake off the shame and isolation.

From raising awareness, Shriver turned to raising money. In 2010, she organized Maria's March on Alzheimer's in Long Beach, CA, and recruited celebrities such as Peter Gallagher, whose mother died from Alzheimer's disease in 2004, and Soleil Moon Frye, whose father, actor Virgil Frye, had the disease at the time and died two years later. Participants paid \$25 to enter and were encouraged to raise funds to support the Alzheimer's Association. In the end, the event raised \$276,000.

In May 2016, Shriver organized the Move for Minds Challenge at Equinox Sports Clubs in multiple cities across the country. The event brought together experts in brain science, nutrition and fitness, caregiving, stress, and sleep, as well as researchers, celebrities, and activists. Participants, who were required to raise or donate a minimum of \$250, took part in events like yoga, guided meditation, and cardiovascular fitness challenges to raise awareness and funds for research on women's brains and Alzheimer's disease.

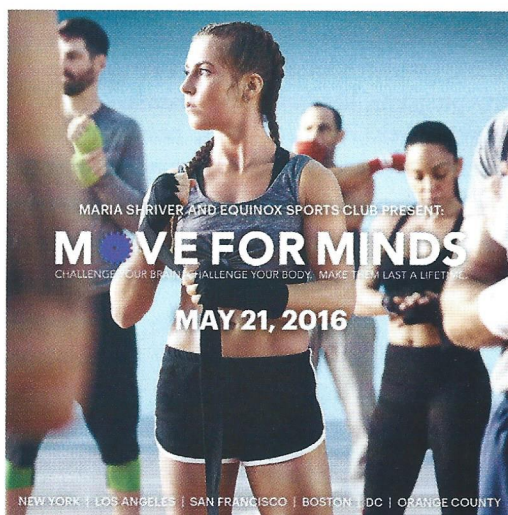
“I wanted to illustrate that Alzheimer's can impact young, vital people who are active and still have a lot of life to live,” Shriver says, “so I brought people together to focus on the disease in a space they wouldn't ordinarily expect.”

DETECTING A PATTERN

In the course of her research and outreach, Shriver began noticing a trend. “Women are shouldering the brunt of Alzheimer's, either as someone living with the disease or as a caregiver,” she says. She found the statistics staggering. Sixty-five percent of all those with Alzheimer's disease are women and 60 percent of caregivers for people with Alzheimer's disease are women, says Heather Snyder, PhD, director of medical and scientific operations at the Alzheimer's Association.

Shriver also noted the persistent misconception that Alzheimer's “is only an old person's disease.” In fact, about 200,000 people in the United States who are living with the disease were diagnosed under age 65. Furthermore, women in their 60s are almost twice as likely to develop the disease as they are to develop breast cancer over the rest of their lives, according to data presented at the 2015 Alzheimer's Association International Conference.

“To date, no one knows why two-thirds of those diagnosed are female,” says Shriver. Alarmed by these statistics and concerned about their long-term effect on the economy and social fabric, Shriver collaborated with the Alzheimer's Association to produce *The Shriver Report: A Woman's Nation Takes on Alzheimer's*, a comprehensive study of the impact of the disease on women. “It was the first time anyone reported that Alzheimer's was a woman's disease and that Alzheimer's disproportionately affects women's brains, and not just because women live longer,” says Shriver.



EXERCISE FOR A CURE Shriver organized Move for Minds with Equinox Sports Clubs around the country to raise money and awareness for Alzheimer's disease.

A CALL TO WOMEN

Shriver believes women can change the trajectory of the disease, and she encourages them to get involved, to demand more gender-specific research, and to support the millions of women caregivers. “I'm trying to galvanize women all over the world to help me change the marketing of this disease. It's not just an older person's disease. And it doesn't affect only the individual diagnosed; it deeply impacts the entire family,” she says. “There are financial, emotional, spiritual, and physical effects that touch everyone's life.”

A year after she published *The Shriver Report*, Shriver was an executive producer on *Still Alice*, a film

about a linguistics professor diagnosed with Alzheimer's disease at age 50. The movie encapsulated many of the themes Shriver has been voicing since her father's diagnosis in 2003.

THE FEMALE CONNECTION

The common explanation for why more women than men develop Alzheimer's disease is that women outlive men and the risk for Alzheimer's increases with age, says Douglas Scharre, MD, FAAN, professor of clinical neurology and psychiatry and director of the Center for Cognitive and Memory Disorders, Center for Neuromodulation at Ohio State University.



PUBLIC SERVICE Maria Shriver with her mother, Eunice, founder of the Special Olympics, who died in 2009; an image from *The Shriver Report: A Woman's Nation Takes On Alzheimer's*, Shriver's comprehensive study on the impact of Alzheimer's disease on women.

But longevity is just one piece of the puzzle. Hormonal shifts are also factors to consider, says Dr. Scharre. "Several theories revolve around menopause-related hormonal changes, but there hasn't been enough research to sort these things out," he says. "Why more women than men develop Alzheimer's is still largely a mystery."

It's a mystery Shriver is determined to solve. "We have to figure out what's happening in women's lives when they're 30, 40, or 50 years old that shows up as Alzheimer's in their 60s and 70s," she says.

The Alzheimer's Association shares Shriver's passion for gender-related issues, says Dr. Snyder. In 2015, the Association convened a "Gender Vulnerability Related to Alzheimer's Disease" think tank to discuss underlying biological mechanisms, the role of hormonal factors, and the impact of lifestyle factors. As an outgrowth of the discussion, the Alzheimer's Association established the Sex and Gender in Alzheimer's grant program, which will award \$250,000 a year for up to three years to six projects. "The money is to be used to investigate and address the gaps in our understanding of the role gender and related genetic, biological, lifestyle, and societal factors may play in increasing vulnerability for Alzheimer's," says Dr. Snyder.

ADVOCATING PREVENTION

Shriver knows her risk of developing Alzheimer's is higher because her father had the disease. "I experience pangs of concern that Alzheimer's may strike me. I think anyone whose family member has battled this disease worries about that," she says. Studies have found that having a first-degree relative (a parent or sibling) with Alzheimer's can raise the risk of developing the disease by 20 to 25 percent, says Dr. Scharre.

To lower her risk, Shriver guards her health. "I try to eat well and live a healthy life. I limit my sugar intake, get regular restorative sleep, meditate, do daily physical exercise, and force myself to exercise my memory and mind," she says.

One of her favorite mental exercises is switching off technology. "Instead of always relying on a GPS, I try to memorize directions to someplace new," she says. "Technology does a lot of thinking for us so I try to use my phone for talking rather than for looking up a forgotten name of a song or movie title, or to navigate a new route."

She also discusses the risks with others. "I talk to other women about what we can do today and tomorrow to protect our cognitive health and the health of our loved ones," she says.

HOW TO HELP

There's much to be done to address the Alzheimer's epidemic, says Shriver. She offers some suggestions for the federal government in *The Shriver Report*, including providing an eldercare tax credit, eldercare leave, elder day care programs staffed by professionals trained in dealing with the disease, intergenerational day care centers, quality control of nursing homes and end-of-life facilities—and promoting eldercare savings programs to set aside money for future health care costs.

Shriver also encourages people to help in any way they can, whether that's caring for a family member with Alzheimer's disease, volunteering to teach art therapy classes to jog a loved one's memory, or sharing stories. Being the daughter of a politician, she also knows the value of the political process. "Vote for those who say they'll make funding for brain-related disease a priority. Educate young people about the disease and the fact that they can make a difference in its course," she says. "Let your voice be heard. Let your federal and local elected officials know this is a priority, that the cognitive health of women is a serious matter worth fighting for."

Indeed, the government is responding to advocates like Shriver. The Alzheimer's Association hopes Congress will increase Alzheimer's-related funding by \$400 million in 2017. And the proposed 2016 federal budget allocated an additional \$350 million for Alzheimer's disease research, a 60 percent boost that will bring total funding to \$936 million.

It can never be too soon, says Shriver. "Unlike when dealing with cancer, even at its most aggressive stages, there's no hope in Alzheimer's. There are no stories of remission or miraculous recoveries. No one says, 'I beat Alzheimer's.' It's the ultimate foe, and you have to be a formidable warrior."

But Shriver believes women are worthy opponents. "Through education, awareness, activism, and expecting nothing less than full commitment from leaders and lawmakers, we can take control and halt Alzheimer's in its tracks."