

**Testimony of Marcia Gay Harden**  
**Hearing on “Changing the Trajectory of Alzheimer’s: Reducing Risk,  
Detecting Early Symptoms, and Improving Data”**

**Special Committee on Aging**  
**United State Senate**

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Thank you Chairman Collins, Ranking Member Casey, and members of the Committee for this opportunity to testify today on the impact of Alzheimer’s disease on my family and families across the country.

As I look around me this morning, I’m grateful to see so many people gathered in this room. But a scary statistic tells us that one or more of us, and certainly one or more of our children, will develop Alzheimer’s disease. There is no known cure, and the symptoms are devastating; every memory of life is wiped away, including forgetting how to breathe and how to swallow. To date, there are no survivors of Alzheimer’s. Unlike cancer and AIDS, many individuals living with Alzheimer’s, like my mother, can’t speak for themselves, because they reach a point in the disease where they are no longer able to speak out about it. Alzheimer’s is an insidious, cowardly disease that needs all of our voices, the voices of families, of our elected officials, and the voices of our nation to galvanize and find a cure. It is my prayer that with your help, advocacy, and funding, this generation is able to celebrate the first survivor of Alzheimer’s disease.

Congress has worked in a wonderfully bipartisan manner to nearly quadruple Alzheimer’s and dementia research funding at the National Institutes of Health (NIH) since 2011, and continues to be deeply committed to providing the Alzheimer’s and dementia community with funding to move research forward. However, more needs to be done so we can discover the cause of Alzheimer’s and find a cure.

Every 65 seconds someone in the United State develops Alzheimer’s disease, and that number will nearly double by 2050. According to the Alzheimer’s Association, an estimated 5.7 million Americans are living with Alzheimer’s in 2018. Almost two-thirds of Americans with Alzheimer’s are women. In truth, it frustrates and saddens me to hear these numbers. More importantly, it angers me — and I have found anger to be a great motivator. Amazing what a person can accomplish when they get pissed off enough.

Alzheimer’s disease first came into my life in 2011 when my strong, witty, vibrant mother was diagnosed. As a daughter and a caregiver, I hope my story will bring awareness to this horrible disease.

Let me tell you a little bit about my mom, Beverly Harden. She is one of the bravest women I have ever met. She raised five children while being stationed all over the world as my dad pursued his career, serving our country as an officer in the United States Navy. For months at a time, mom would be alone with five children to feed, bathe, teach and love. While we were living in Japan, she discovered ikebana — the ancient art of Japanese flower arrangement. She found that ikebana could transform her home into a place of spiritual reflection and beauty. Ikebana’s most important rule of forming an asymmetrical triangle with the flowers — representing shin,

soe, and hikae — or heaven, earth and man — kept her grounded and connected to the beauty of life through nature. Mom went on to become the President of Ikebana International's most distinguished chapter, Chapter 1, right here in Washington D.C, but she doesn't remember any of that. She accompanied me to the Oscars in 2001. She doesn't remember that. Her beloved husband passed away in 2002. She doesn't remember that either.

One of the first times I noticed my mom having memory problems was around 2005 when we were traveling to Canada. We had boarded the plane and she couldn't remember where she had just put her passport — so she checked her purse. Several minutes later, she forgot again, and so checked once more. And again, a third time. She became frantic, she was aware that something was wrong and that she shouldn't keep forgetting where her passport was. She didn't want my help; she was in anguish, wanting to string the moments together herself, with no gaps. Over time, those kinds of moments became more frequent and in 2011 she was diagnosed with Alzheimer's disease.

As we all know too well, Alzheimer's disease causes memories to evaporate. One minute a person can recall a detail of their favorite novel, the function of a spoon, or the fact that tulips bloom in spring, and the next minute it has disappeared. Eventually the names, and finally faces of loved ones, are also memories that have evaporated, and soon, the meaning of their lives evaporates. So it is for my mother.

Today 50 million people worldwide suffer this evaporation. Rich, fertile minds, PhDs and scientists, plumbers and dancers, Presidents and senators, doctors, inventors, teachers and firemen, the disease doesn't discriminate. These people are now deprived of the validation of the memory of their lives. They don't remember who they were. They don't know who they are, they forget how to talk, how to walk, how to arrange flowers. Watching my mom forget herself and her many contributions to life — it pisses me off. So my siblings and I do what my father taught us to do — we “pull ourselves up by the bootstraps” — never mind that we wear high heels. We know what he meant!

As a family, we focus on her care, and on maintaining her dignity. We've sold my mother's home in anticipation of the mounting costs of caregiving. It was one of the hardest decisions that we've had to make so far; the loss of her home is something that we all felt, with such a dread and sense of helplessness that it has somewhat devastated us. I keep reminding myself we are doing the best we can, with the tools and knowledge that we have. We want things to be as they were before but the disease continues to march forward. Our funds are limited, these are uncharted waters, and we've had to adjust, to prepare for the unknown, to calculate all possibilities and most importantly ensure her comfort, care, and safety. My mom now lives in a smaller house, located on a lake with birds and familiar neighbors close by. It is near medical resources and a church, as well as my sisters who shower her with love and visits, and caregivers who take wonderful, dutiful and exacting care of her as she ages with Alzheimer's. But we don't know what the future holds, and we are scared. Will we eventually have to give up our own jobs to care for my mother? What will happen when the money runs out?

Did you know eighty three percent of help provided to older adults in the United States comes from family members, friends or other unpaid caregivers? And nearly half of those caregivers provide care to people with Alzheimer's. Last year, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid assistance — valued at \$232.1 billion. Unpaid care.

It infuriates me that this is how Alzheimer's becomes a stealthy thief, robbing families of their finances and security, and forcing its victims to live only in the moment. For my mother there is only the present, with no connection to her past, without the rich tapestry for her life to tell her story. No dimension, just dementia. I see her concentrate, I see her try to speak the right words, I see her try to connect the memory to words and through it all, I see her eyes smile, but it seems to me, the smile is a little bit wounded these days.

There is no medicine yet, no surgery yet to grasp the dangling thread of memory, to rethread the needle and weave it back into her tapestry and connect thoughts to memory and life experience, to allow her to remember her life. Instead, as the patient and family wait impatiently, more threads unravel, more dangling thoughts, the tapestry of her life slowly disintegrates, the picture is blurred and memory is lost.

This disease has no dignity, and yet, my mother has somehow managed to keep hers. And even as the pitch-black darkness of this hideous disease advances, the core of my mom — her elegance and humor and love of family and God — had remained the same. I think of it as her light that cannot be extinguished.

As I watch my mom decline, I find myself worrying about me or my children having Alzheimer's. My mom always told me to repurpose my pain, to do something useful, so I read a lot about the disease and ways to reduce my risk — things like exercising, a healthier diet, and sleeping better.

Alzheimer's has changed me. I've become an outspoken advocate. I've done campaigns to raise awareness of the early signs of dementia and Alzheimer's. The more I learn about the disease, the more motivated I am to make sure that people are educated about it.

It is so important for people and doctors to be aware of the early signs of Alzheimer's disease and other dementias. In 2015, I partnered with the Administration for Community Living at the Department of Health and Human Services for a nationwide campaign called "What is Brain Health?" that aimed to raise awareness about brain health while empowering older adults to make the most of their brains as they age — with a particular emphasis on early detection and diagnosis. I learned that approximately 50 percent of individuals with Alzheimer's and other dementias have not been diagnosed and of those who are diagnosed with Alzheimer's only about 33 percent are aware of their diagnosis. My participation in the "What is Brain Health?" campaign only solidified my belief in the value of raising awareness about Alzheimer's and brain health, because when people are diagnosed earlier, they can have hard but empowering conversations with family that will allow them to take some control over their destiny. They can take steps to create a care plan with their families and their physician. They can control what time they have left before the darkness takes over. Early diagnosis also allows people to access available treatments, participate in support services, and if they choose to, enroll in clinical trials.

Last month, I worked with Maria Shriver and the Women's Alzheimer's Movement during their national initiative Move for Minds — and was especially hopeful at the work they are doing. I learned from them that women are at a greater risk for this disease. According to the Alzheimer's Association, 2 out of 3 brains that develop Alzheimer's belong to women. Why? I've always known our brains are different and I was inspired by the call to action to research the why of it all —the how of it all. What role hormones, sleep, having babies and menopause may play in Alzheimer's disease? We must fund more research on women's brains.

As scientists continue to search for a way to prevent, cure or slow the progression of Alzheimer's through medical research, public health can also play an important role in promoting brain health and cognitive function, and reducing the risk of cognitive decline. It is imperative that we as a country invest in a nationwide Alzheimer's public health response to achieve a higher quality of life for those living with the disease and their caregivers.

One of the ways we can make that investment is through legislation introduced by Chairman Collins and Senator Cortez Masto, called the BOLD or Building Our Largest Dementia Infrastructure for Alzheimer's Act. Endorsed by the Alzheimer's Association, the BOLD Infrastructure for Alzheimer's Act would create an Alzheimer's public health infrastructure across the country to implement effective Alzheimer's interventions and focus on important public health issues, such as: increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.

Every little act we do, does make a difference. Caregivers always feel guilty they can't do enough, but I want caregivers to know that we have to be gentle with ourselves. Being in the moment with the person, knowing they have an ability to recognize the familiar even if they can't verbalize it, is comforting. Once my mother said to me: "I don't know who you are, but I know you are important to me. When you came into the room, your face made me feel happy." I've learned to say to my mom, "It's okay if you don't remember me, I will always remember you."

There is nothing good about Alzheimer's — it is not a disease where one can make lemonade from lemons. When I think of my mom, I think of the beauty of her Ikebana, her delicate creations with lines for shin, soe and hikae, and how she was before. I don't want Alzheimer's to be her legacy. And yet, through it all, my beautiful mother has managed to teach me, even through the destruction of her capabilities and creativity, that there is such a thing as an indestructible spirit. It is because of that indestructible spirit that I know she would want to help others by raising awareness about this horrible disease. Through a daughter's eye, I share story in hopes of keeping her legacy alive.

The battle against Alzheimer's is a battle we must win. If we don't, it will cripple our nation. I want to close with some words from my Navy Captain father who was fond of quoting General Patton, their spirits were similar, despite their different military branches. This was one of his favorite Patton quotes: "All men are afraid in battle. The coward is the one who lets his fear overcome his sense of duty. Duty is the essence of manhood."

We must pull ourselves up by the bootstraps. We must do our duty to the American people and fund and fight this battle, and we will win.

Thank you for your time.