

Maria Shriver
TESTIMONY
3-25-2009

I'd like to thank the Alzheimer's Study Group for their service -- and the committee for asking me to speak here today -- even though I wish I didn't qualify.

Good morning. I'm Maria Shriver -- and I am a child of Alzheimer's.

For many years, my father, Sargent Shriver, would come here to The Hill HIMSELF to testify before congressional committees. He came to get increased funding for his beloved Peace Corps -- and for all the War On Poverty programs he started, including Head Start, Vista, Job Corps, and Legal Services for the Poor.

My father was legendary for the way he worked this building. He knew every Senator and Congressman by name. He knew their careers, their interests, their politics . . . AND their soft spots.

Sargent Shriver was an idealistic, intelligent, OPTIMISTIC public servant -- sharp, witty, a walking encyclopedia -- his MIND a beautifully-tuned instrument that left people in awe AND inspired.

That was then . . . TODAY he doesn't know my name or who I am. To be honest, that's still really difficult to wrap my OWN mind around. But that's the heartbreak and the REALITY of Alzheimer's. A reality that's terrifying AND incomprehensible.

When my Dad was first diagnosed in 2003, I felt confused, powerless, and alone. There was little information -- and even less HOPE.

My mother, my four brothers and I felt we were entering a world that was dark, depressing, and scary. People didn't TALK about Alzheimer's -- they WHISPERED about it. It was a diagnosis shrouded in shame.

We struggled with learning about medication and care-giving -- with issues of our father's diminishing independence. Trying to EXPLAIN to him why he could no longer drive. Trying to TELL why he could no longer do many of the things he loved MOST in this world, like giving speeches about public service. When the invitations came in, we'd just send his regrets.

I know that when people look at Alzheimer's families from the outside, they see the dependent, childlike PARENTS now cared for by their OFFSPRING -- and it seems that the roles are simply REVERSED. Not so.

The truth is, no matter what our age, we feel like CHILDREN. No matter who you are, what you've accomplished, what your financial situation is -- when you're dealing with a parent with Alzheimer's, you YOURSELF feel helpless.

The parent can't work, can't live alone, and is totally dependent, like toddler. As the disease unfolds, you don't know what to expect.

As a doctor once told me, "Once you've seen one case of Alzheimer's . . . you've seen one case of Alzheimer's."

In fact, back then, there was so little information about the disease that I wrote a book myself, called, *"What's Happening to Grandpa?"* At the time, I said I wrote it to help my children understand what was happening. In truth, I wrote it to explain Alzheimer's to myself.

But when I wanted to turn it into a television special -- to shine some light on this subject -- no one was interested. I was told Alzheimer's wasn't BIG enough -- it was just "an old person's disease".

As my father's situation deteriorated, my brothers and I felt we wanted to do something that captured who our father was and told his story.

Along with the Chicago Video Project, I executive-produced a film called "The American Idealist", about his life and legacy in government -- so that people would remember his intellect, energy and passion -- even if HE couldn't.

Then almost out of nowhere, came what I call The Alzheimer's Turning Point. It happened in March, 2007, when the New York Times reported that the number of people with Alzheimer's was **BALLOONING** -- rising by 10% in just the previous five years. They reported that fully 13% of Americans had Alzheimer's -- that meant one in EIGHT people over the age of 65. And UNLESS a cure were found, there would be more than 13 MILLION people with Alzheimer's by 2050. The number, as you've heard this morning, has been revised even further upward since then.

THAT was the wakeup call Baby Boomers needed. After all, WE'RE the generation who believed our BRAIN-span would match our LIFE-span.

But now we were confronted with an EPIDEMIC -- an epidemic that wasn't just happening to "THEM". An epidemic that would happen to "US", too. And that scared us to death.

All of a sudden, it seemed to me that people REALLY started paying attention, and Alzheimer's became front-page news.

And that's when HBO came to me and said, "We need to take an in-depth look into Alzheimer's disease, and we want you to be involved."

So, starting on Mother's Day, May 10th, HBO will air the most comprehensive television event ever about Alzheimer's disease. It's called the Alzheimer's Project. There will be four broadcasts and a companion book -- focusing on the cutting-edge SCIENCE -- the issues of CARE-GIVING -- how one LIVES with the disease -- and the CHILDREN AND GRANDCHILDREN of Alzheimer's.

I'm excited to be executive producing this project along with HBO's Sheila Nevins -- because I truly believe it will change the way we look at Alzheimer's.

It's TIME for all this attention. Fully a THIRD of Americans now have direct experience with this disease. People come up to me all the time to ask for advice and guidance.

And believe it or not, there are getting to be almost as many kids actually "babysitting" a grandparent with Alzheimer's at home -- as are babysitting for little kids. THAT'S where we are.

Of course, most of the unpaid care-giving is done by women -- but luckily, THAT'S also changing. Increasingly, men are stepping up to the plate.

Which brings me back to my brothers. I'm in AWE of what they do. My brothers take my Dad out to the Orioles games. They sit and joke with him, talk guy-talk to him. They take him to their kids' piano recitals and basketball games.

Former Peace Corps volunteers will see him, know he has Alzheimer's, and still come up to him. They take his hand, and tell him stories.

It doesn't matter that he doesn't know who they are -- or that he doesn't even REMEMBER the Peace Corps. What matters is that I know for sure he's comforted by the warmth of the human connection.

I know that all in all, my family is one of the lucky ones. We're truly blessed we're able to keep our Dad at home.

We're blessed to have the resources to pay patient and loving caregivers, who help us take care of our Dad and make him feel loved. I'm in awe of THEM, too.

But millions of others aren't as lucky. Many are forced to quit jobs to stay home -- or go through the wrenching process of sending the parent away to a facility -- feeling judged and mortified and ashamed that they can't care for their loved one themselves. For so many, the financial, emotional, and spiritual cost is just way too much to bear.

My hope is that as the veil is lifted, as information and funds are available, they'll see that they're not alone -- that there's nothing to be ashamed of, that there's hope out there, because we're FINALLY making Alzheimer's a national issue.

We HAVE to put Alzheimer's on the front burner, because if we DON'T, Alzheimer's will not only devour our memories -- it will cripple our families, devastate our health care system, and decimate the legacy of our generation.

But let me get back to my father. At the age of 93, my Dad still goes to Mass every day. And believe it or not, he still remembers the Hail Mary But he doesn't remember ME ... Maria. I'd be lying if I didn't admit that that STILL makes me cry.

But even so -- in the past 6 years, I have gone from hopelessness to HOPE.

I have hope, because things are CHANGING out there:

I've seen inter-generational day care centers -- where toddlers and Alzheimer's patients spend the day together. They eat together, they dance together, and have story-time together. It's quite moving to behold.

And we're building inter-generational PLAYGROUNDS in California, so Sandwich Generation people like ME -- who are taking care of kids AND parents -- can go to one place with both of them.

I've ALSO gotten hope from my OWN children. I watch how they talk and laugh with my father. They don't get bogged down in the sadness. My kids and my nieces and nephews ALL accept my Dad for who he is today -- and that's been a lesson for me.

I have hope because public hearings like this -- high-profile work like the Alzheimer's Study Group report -- the coverage we'll get today -- and the TV shows and books we're doing ... are bringing Alzheimer's out of the BACK room and into the LIVING room of our nation.

And most of all, I have hope that this committee will do the BOLD thing, the COURAGEOUS thing -- and use The Alzheimer's Study Group's report as a roadmap for the real legislation we need, to stem the tide of what promises to be a horrific epidemic -- the disease itself, AND its impact on our families and our health care system.

I know many of you know of someone -- or even know someone CLOSE to you -- who's struggling with this disease in their family. I know you've seen the pain in the eyes of someone who has to watch powerlessly as it takes their loved one down ... and sometimes even tears at the fabric of the family itself.

That's why I know you'll HAVE the courage to do the right thing. And make no mistake, I know it'll TAKE courage to implement some of these BOLD recommendations.

But I know for SURE that if you MAKE that major commitment to brilliant scientists like the ones I'VE met in laboratories around the country -- they WILL produce drugs to slow Alzheimer's down -- and maybe even prevent it.

So let's get busy NOW and do what we have to do -- to spare millions of Americans in the future the PAIN of watching someone they love die a mysterious death on the installment plan.

If we DO -- I am convinced -- TRULY convinced -- that we Baby Boomers WILL be the generation who tells our GRANDchildren . . . that believe it or not, there ONCE was a time . . . when there was NO cure for Alzheimer's.

Thank you.

##