

MARILYN BLUM
OWINGS MILLS, MD
SUMMARY

My husband Steve is one of as many as half a million people under age 65 who have early onset dementia. He was diagnosed two years ago at age 60, although his memory problems started even earlier. Steve's father was diagnosed with dementia in his 40's and died in a state mental institution 10 years later, while Steve was still in college.

Steve had been a very successful CPA and chief financial officer of a public relations firm. His memory problems were already noticeable when his firm was downsized and he was laid off. He declined considerably after he retired.

Steve's internist dismissed our concerns about Alzheimer's, even when we told him about Steve's father. He diagnosed depression and prescribed antidepressants. I wasn't satisfied. We found a psychotherapist who agreed this was not depression. After extensive tests, we got the diagnosis of probable Alzheimer's.

Steve has suffered huge personal loss because of his Alzheimer's. He had to give up our personal finances – a major blow to a successful CPA. He had to give up driving. Because we were younger than most couples dealing with Alzheimer's, we faced unique problems – loss of income, social isolation, and lack of meaningful activities.

Our best source of help has been the Alzheimer's Association. Through them we found a program organized for people with early-onset disease, which included educational sessions and separate counseling sessions. Both Steve and I found new friends there who understand what we are going through and share ideas about how to tackle our daily challenges.

The 24/7 helpline has been a godsend. Doctors can help with medical issues, but they are not available at 11 at night when your husband is yelling at you. The Alzheimer's Association's Call Center is.

It was not safe for Steve to be at home alone. For nearly two years, I was working 24 hours a day, 7 days a week to keep him socially stimulated and engaged in day-to-day activities. At the same time, I was looking after my 92-year old father who has health problems of his own. When I reached the end of my rope, I enrolled him in an adult day program, which he attends 5 days a week. He thinks about it as his volunteer "job."

I am determined to keep Steve at home as long as possible but like all caregivers, I need help. I urge Congress to continue its support of programs like the 24/7 helpline. We also need greater awareness, standard procedures to recognize early onset Alzheimer's and better tests to diagnose the disease at its earliest stages.

I urge you to increase funding for Alzheimer research to find better treatment and prevention. I want to be able to tell Steve that his daughter, his granddaughter, and the grandson on the way will not have to face what I am dealing with today.

STATEMENT OF MARILYN BLUM

OWINGS MILLS, MD

to

**AGING SUBCOMMITTEE, SENATE HEALTH, EDUCATION, LABOR & PENSIONS
COMMITTEE
MARCH 20, 2007**

Good morning Senator Mikulski and other distinguished guests. It is an honor to be here. My name is Marilyn Blum and I live in Owings Mills, Maryland. I represent one of the millions of family caregivers who struggle daily to confront the challenges of this terrible disease. I am also here to tell you that Alzheimer's is no longer just our parent's disease. It has hit the baby boomers and it is not going away.

My husband Steve is one of the 200,000 to 500,000 people under age 65 with early onset Alzheimer's disease or other dementias. We found out that he had probable Alzheimer's disease two years ago at age 60 a diagnosis that was not a surprise given Steve's family history. His father was diagnosed with dementia in his 40's and was eventually placed in a state mental hospital after he became violent. He died in the state institution about ten years later, while Steve was still in college.

When Steve's memory problems first started, he was a very successful CPA employed as the chief financial officer of a public relations firm. The CFO job was demanding but Steve had always been able to handle the workload. Suddenly he started going to the office seven days a week. He said it was because his assistant had been let go and he had to do her work as well as his. He also started getting lost in familiar places. Whenever we drove somewhere together I had to give him specific directions like "turn right at the stop sign" or "watch out for the red light". He gave wrong answers when asked questions--particularly about money--which was odd for a CPA. Although I didn't know it at the time, he also stopped doing maintenance on the house and cars, which was not normal for him. That led to later challenges for me, because I had to play "catch up" on things that weren't done timely, one of which caused our basement to flood.

Steve's memory problems continued for several months. Eventually the PR firm was bought by a larger company who downsized the firm. Steve was laid off – a development that turned out to be a blessing because it was becoming increasingly obvious to Steve's superiors that he could not perform the duties of his job. The layoff allowed Steve to end his career with dignity and helped him accept that retirement was the next logical step.

Steve declined considerably after he lost his job. We immediately made an appointment with Steve's internist. During the consultation we mentioned that Steve's father had been diagnosed with dementia at a young age but the internist repeatedly dismissed our concerns. The internist diagnosed depression and put Steve on antidepressants. I wasn't happy with the doctor's diagnosis so I found a good therapist through a friend. Steve began seeing the psychotherapist who realized that the memory problems were not depression. After an extensive round of tests, we found out that Steve had cognitive impairment with probable Alzheimer's disease.

The diagnosis turned our lives upside down. I had to convince him to relinquish responsibility for our personal finances. That was a major blow because as a CPA he was always on top of our financial situation and suddenly we had to hire an accountant for the first time in our lives. He also had to give up driving which was perhaps the most painful loss. He always loved to drive and kept our cars in spotless condition - we joked about what good prices we got when we sold cars, because he kept them so well. He has gradually come to accept that I don't want him to drive, but we have daily conversations about him buying a new car.

We were referred to the local Alzheimer's Association chapter which has been the absolute best source of help and support over the last few years. No matter how many friends and family members there are to help, no one can give you support like the Alzheimer's Association because they are the experts. Through the Alzheimer's Association we attended four different support groups before we finally found one that met our needs. Most of the support groups were geared toward older people who were not dealing with the same issues that we were facing including loss of income, social isolation and lack of meaningful activities for younger persons. We eventually enrolled in an eight week pilot program for individuals with early-onset Alzheimer's. The program included educational seminars about the basics of Alzheimer's disease, as well as separate counseling sessions for caregivers and individuals with the disease. The program was a lifesaver for both of us. Steve got to spend time with people like him and make new friends. I met people who knew what I was going through and learned from other caregivers how to tackle the daily challenges of being an Alzheimer caregiver. I heard about the Association's helpline that is available 24 hours a day, 7 days a week to answer questions about the disease, provide information about available services, offer counseling in crisis situations or just listen if I need someone to talk to about my fears and frustrations. Doctors can help deal with the medical aspects of Alzheimer's but you can't call them at 11:00 p.m. when your husband is agitated and yelling at you because he can't remember where he put the television remote.

I also learned what I could do to help keep Steve socially stimulated and engaged in day-to-day activities. When I reached the end of my rope after being with Steve 24 hours a day, 7 days a week for nearly two years, the Association suggested I enroll Steve in an adult daycare program. At first, Steve refused to participate. However, I read a book that said to tell Steve that going to the daycare center was a volunteer job. Steve now volunteers at the daycare center five days a week and it makes him feel like he still has a job. With Steve at the daycare center I don't have to worry that he's home alone and I can continue looking after my 92-year old father who has health problems of his own. However, I'm very aware that our future is uncertain so I applied for the Maryland respite care program. I recently learned that unfortunately there is a greater demand for respite services than funds available so I am now on a waiting list.

I am determined to keep Steve at home as long as possible but I can't do it alone. We must continue programs that support caregivers, including the Alzheimer's 24/7 helpline and we have to increase funding for research to find better treatments. We also need greater awareness and standard procedures in place to recognize early-onset Alzheimer's disease and better tests to identify the disease at the earliest stages. That is why I'm so grateful to you Senator Mikulski for introducing the *Alzheimer's Breakthrough Act* and for your outstanding leadership on Alzheimer's issues in the Senate. I want Congress to pass the "Alzheimer's Breakthrough Act" as soon as possible so I can tell Steve that his daughter, granddaughter and

grandson on the way will not have to confront what I'm dealing with today. Congress should pass this bill not just for my family but also for the millions of other families who are represented in this room. Unless we act now, another generation of Americans will become the newest set of statistics to fill the pages of a report about Alzheimer's. We can avoid this horrible scenario but only if policymakers make Alzheimer's an urgent national priority. Thank you again for inviting me here today.