

Special Committee on Aging Hearing on Alzheimer's

May 14, 2008

Suzanne Carbone

Good morning. My name is Suzanne Carbone. Thank you for the opportunity to talk with you about our family's experience with Alzheimer's disease. My husband, Bob Carbone, was diagnosed with Alzheimer's eight years ago.

He was born in Plentywood, Montana, where his immigrant father was a section foreman for the Great Northern Railroad and his mother was a homemaker. Bob earned a Masters degree from Emory University, and a PhD from the University of Chicago. He was the Special Assistant to President Fred Harrington at the University of Wisconsin, and later became the Dean of the College of Education at the University of Maryland. Always interested in the political process, he ran for the Maryland State Legislature in 1982.

In January 2007 Bob moved into assisted living, when caring for him at home was no longer an option. Today, he can no longer speak a coherent sentence, cannot dress himself, take care of his personal needs. We are not sure if he recognizes us as his family.

I am just one of millions of caregivers who are faced with difficult and heart-breaking decisions of care. Every day I meet yet another caregiver who needs help and doesn't know where to turn.

Upon a diagnosis, families are swept into a sea swell as they are confronted with changing levels of ability and changing patterns of behavior of their loved one. My husband and I were no different. We left the neurologist's office with a few prescriptions and minimal advice. We should have been able to leave the office with something that said, "These are the areas in your life that will change, and you need to address during phases 1,2,3,etc. of the disease. Here are the best contacts, the top resources in your area to whom you can turn."

I am convinced that we need to transform the way we support patients and families caught in the tangles of this disease.

I struggled to patch together a system of support, drawing on public and personal networks, to cope with issues of physical and emotional care, financial and legal planning, transportation and driving, in-home care, day care, and finally assisted living. It felt as if we were on shifting sand, because as soon as I had a care plan in place, my husband's needs changed, and I had to seek out yet additional solutions to our situation, and I'd have to convince him to accept it.

One of the most useful resources I found was a six-week caregiver training program funded in part by a grant from the Montgomery County, Maryland, Department of Health and Human Services, Aging and Disability Services.

From it I learned about the process of dementia, its stages and treatments-about communication needs, and techniques to use during various stages of the disease, about environmental modifications, what to expect during the middle and late stages, and finally, issues of hiring and working with in-home care, day care, respite care, and assisted living. The workshops were invaluable, and provided me with insight, information, skills, support and contacts. I urge that this type of program serve as a model and be replicated widely in local communities.

I am still working full-time as a manager at the Rockville Library in Montgomery County, Maryland. I must work in order to pay for the care my husband receives. He now lives at Brooke Grove Assisted Living in Olney, Maryland, where he receives excellent care. However, the costs are huge - \$73,000 last year. If I become ill, how will we manage? Given the fact that my husband's father lived to be a hundred years old, it's entirely possible that my husband will outlive me, at which time the responsibility of his care would be passed on to our two children. We must find ways to help families with this tremendous financial burden.

In conclusion, I look forward to the day when there are stronger, more cohesive, community-based networks of resources to support patients and families with Alzheimer's. I have been encouraged by the idea of Memory Centers, as seen at several universities throughout the country, which provide access to evaluation, diagnosis, and treatment, and referrals to caregiver services and support groups. I wish we had had such a resource for Bob.

I call on policymakers to pass legislation to support individuals with Alzheimer's and their families, especially legislation that would develop and improve individual patient-based care plans, provide families financial assistance in caring for loved ones with Alzheimer's disease, and that expands paid leave for caregivers.

I urge Congress to immediately increase the investment in research to find better ways to diagnose and treat Alzheimer's.

I thank you for the opportunity to share a portion of my family's experience with Alzheimer's, and commend you for holding this hearing to draw attention to this critical issue.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's. For more information call (800) 272-3900 or visit www.alz.org.

Alzheimer's Association Memory Walk™ is the nation's largest event to raise awareness and funds for Alzheimer care, support and research. Held annually in hundreds of communities across the country, this inspiring event calls on volunteers of all ages to become champions in the fight against Alzheimer's. For more information call (800) 272-3900 or visit www.alz.org.