Senate Special Committee on Aging

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# Testimony on Alzheimer's Disease

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Good morning. Chairman Kohl, and other distinguished members of the committee. My name is Suzanne Carbone. Thank you for the opportunity to talk with you about our family’s experience with Alzheimer’s disease.

In 1906 Dr. Alois Alzheimer presented the clinical and pathological characteristics of the first case of what would later be termed “Alzheimer’s disease”. At this time—over 100 years later—no effective diagnoses or treatment exists to prevent, reverse, or stop this devastating disease that robs patients of their identity and robs families of their loved ones.

My husband, Bob Carbone, was diagnosed with Alzheimer’s eight years ago. In many ways, his story is a classic American success story. He was born to in Plentywood, Montana, where his immigrant father was a section foreman for the Great Northern Railroad and his mother was a homemaker. Relying on his sharp mind and love of learning, Bob earned a Masters degree from Emory University and PhD from the University of Chicago. He was the Special Assistant to President Fred Harrington at the University of Wisconsin, and before his diagnosis, was 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 my husband moved into assisted living, when caring for him at home was no longer an option. I am just one of millions of caregivers who are faced with such a difficult decision. Every day, I meet another caregiver who needs help and doesn't know where to turn. Our country is not prepared for the emotional, physical, and financial impact of this disease.

I am here today to share with you some of  the emotional, and financial impacts that Alzheimer’s disease has on patients and families, to recommend a new model of support for patients and families, and to urge policymakers to immediately increase the investment in research to find better ways to diagnose and treat Alzheimer's.

Alzheimer’s is a confusing, inconsistent and deceptive disease. It slips into households across America like a sly ghost. Before the diagnosis, I sensed that our lives were beginning to be affected by something I did not understand. The changes in behavior in my husband over many years were, I now realize, not because of lack of love for me, nor were they, as they most certainly seemed to be, symptoms of marital discontent. The changes were part of the disease, and the result of his fear and confusion as he became aware that some part of his mind was shutting down, and that the ghost of Alzheimer’s was beginning to inhabit his being

Ultimately, my husband was diagnosed with Alzheimer’s. However, since we still do not have adequate diagnostic mechanisms to differentiate between Alzheimer’s and other dementias, how can we be sure it’s really Alzheimer’s, and how can we be sure he is getting the treatment he needs. According to Katie Masloow’s study for the Alzheimer’s Association, Alzheimer’s Impact on the Nation: Prevalence, Cost and the Leading Issues in Clinical Care and Caregiving, “...most people with Alzheimer’s disease and other dementias do not have a diagnosis in their medical records.”

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. Bob left the neurologist’s office with a few prescriptions and an admonition from the doctor to be “good to me”, as he explained that our experience with Alzheimer’s would be easier for Bob than it was for me. I left with a determination to extract something positive from this devastating news.

With the perspective that I now have, I am convinced that we need to change 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. I felt we were standing on shifting sand, because as soon as I had a care plan in place, my husband’s needs changed, and I would need to seek out yet additional solutions to our situation.

The Alzheimer’s Association provided useful support, but I urge that it develop stronger community-based networks of supports among stakeholders, so that families have quick and visible access to the resources they need on a local level. My husband and I should have been able to leave the neurologist’s office with something that said, “These are the areas of your life that will change and that you need to address during phase 1, 2, 3, etc. of the disease. Here are the best contacts, the top people in your area, i.e. Montgomery County, to whom you can turn.”

One of the most useful resources I found was a six-week care giver training program I attended in 2006, created by Judy Hennessey for the Alzheimer’s Association, and funded in part by a grant with the Montgomery County, Maryland Department of Health and Human Services, Aging and Disability Services. It was called Meeting the Challenges of Dementia: A Hands on Training Program for Family Caregivers.

In this training program I learned about the process of dementia, its stages and treatments. I learned about communication needs and techniques to use during various stages of the disease, about environmental modifications, needs 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 care giver workshops provided skill development and acted as a support group for participants, providing a forum for participants to share their stories and learn strategies for coping with what is ultimately, the loss of people we love. The workshops were an invaluable experience, and provided me with insight, information, skills and contacts. I urge that this type of program serve as a model and be replicated and distributed widely.

I am still working full--at a 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, and this past year, they amounted to $73,000. If I become ill, how will we manage? I must stop working sometime, at some age, and 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 summary:

1. I support the extraordinary efforts of the Alzheimer’s Study Group in its efforts to develop a national strategy to address the multiple issues of Alzheimer’s disease. I have read the documentation on their work, and hope that I can contribute to their effort in some way.

2. I support the development of community based networks of support; accessed through Memory Centers (similar to Cancer Treatment Centers). Please note the Memory Center at the University of Wisconsin model. This would be the entry into a system which would specialize in preventing and treating dementia. (At this time, there is disagreement whether it should be neurologists, geriatricians, psychologists.) It would also act

as a referral center to the host of support services patients will need as the disease progresses. These might include, for example, local chapters of the Alzheimer’s Association, replications of The Friends Club (Bradley Hills Presbyterian Church model), financial planning advocates, elder care lawyers, case workers assigned to help families navigate through the system of resources.)

3. I urge the improvement of patient-based, individualized care plans (exercise, brain games, photos of family, structured environments with customized goal-setting for individuals.) Care centers say they have plans for patients but they are not adequately staffed nor applied, and most patients are still treated as a group, rather than as an individual. We need more health care workers in the labor force who are specially trained in Alzheimer's care, similar to proposals put forth by you, Senator Kohl, and your colleague Senator Boxer.

4. I appreciate that legislation authored by Senators Mikulski and Menendez is currently pending, to provide families financial assistance in caring for loved ones with Alzheimer's disease, and encourage Congress to act on these bills immediately. I also encourage Congress to expand the existing Family and Medical leave law to provide paid leave for family caregivers and understand that legislation in currently pending on this issue.

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.