

United States Senate Committee on Finance
Chronic Illness: Addressing Patients' Unmet Needs

Testimony of Mary Margaret Lehmann

July 15, 2014

Good afternoon Chairman Wyden, Ranking Member Hatch and members of the Committee. On behalf of caregivers for individuals living with Alzheimer's disease and other dementias, thank you for the opportunity to testify before you today on the important topic of chronic care.

Alzheimer's is a devastating, progressive and ultimately fatal disease. It currently impacts more than 5 million Americans living with the disease and their 15.5 million caregivers. These men and women living with Alzheimer's are husbands and wives, mothers and fathers, sisters and brothers, business leaders, medical professionals, Republicans and Democrats. My dear husband Ken is one of them.

I am honored to be here today to share our story and discuss the issues facing individuals living with Alzheimer's and their caregivers. The more we share our story and talk about Alzheimer's, the less of a stigma it will become for others facing this disease. While Ken is fortunate enough to have a devoted care partner to advocate for him and a definitive diagnosis, a care plan to ensure that he lives as well as possible with Alzheimer's was not made available to us and our journey to get here was long and difficult. There are many who live with the disease that never get the care and support they need.

Ken's diagnosis came in October of 2009, however the first signs of Alzheimer's were showing as far back as 1995. It was then that I first began noticing many of the warning signs: becoming withdrawn from friends and social situations, difficulty navigating familiar places, and financial issues. Ken even communicated his frustration over difficulties at work and an inability to learn new computer skills. Since we shared an internist whom we both liked, I would report these signs to him. Our internist brushed off my concerns that these signs may be something more serious, often saying, "these things happen." Not once did we suspect it was Alzheimer's. The wakeup call, however, came when we declared bankruptcy because these symptoms led to the mismanagement of our finances.

We were left thinking, "How could this ever have happened to us?" Finally, I encouraged Ken to see another doctor to learn the reasons behind the changes in his behavior. After seeing a total of four neurologists and three internists, Ken was finally diagnosed with Alzheimer's disease. Our story is not unique. Many families struggle to get a definitive diagnosis of Alzheimer's disease, just like we did. Following his diagnosis, his internist prescribed him Aricept and said he would see him the following year. Ken only shared the news with me, our children and his sister for fear of how others would react. After receiving the diagnosis, he went through what we call The Three D's: denial, depression and despair. We were given the diagnosis, but no information on what to expect, how to deal with symptoms or even how to manage his atrial flutter along with his Alzheimer's. In fact, I took a magazine from the doctor's office that had an article on Alzheimer's, and for a while that was my only resource.

After visiting many neurologists, we were finally able to find one with experience in treating patients with Alzheimer's. Today Ken is a patient of The Center for Memory and Aging in St. Paul and, along with the Alzheimer's Association, we have developed a plan and strategy for not just Ken to live well but also for me as his care partner. Through the Alzheimer's Association we were also able to find new resources for patients and their caregivers and strategies that empower Ken to be independent. From this new network we have also learned that our story of financial hardship associated with the disease is not unique.

In many ways I see my role as his care partner much like that of an operations manager. I try to ensure that Ken is as independent as he can be. We make a concerted effort to engage in social activities and for Ken to exercise his mind and body through creative expression. For me, I have found a wonderful support network through several caregiver support groups where we can share our experiences, trade strategies and find comfort in sharing our burdens. With a disease like Alzheimer's, it is not only the individual who needs care and support, but also their care partners.

Throughout this experience I have learned that there are deficiencies in our health system when it comes to dealing with Alzheimer's. Far too many physicians are not familiar with how to properly advise patients and their caregivers. Additionally, there is a lack of coordination between Ken's various physicians. He sees an internist, cardiologist and neurologist to deal with various conditions. Ken carries a list of his medications to each appointment to ensure that each physician is aware of what his other health care providers have prescribed for him. Sadly this is more the rule than the exception for many individuals with Alzheimer's and their caregivers.

Alzheimer's as a Chronic Condition

Alzheimer's disease is a dramatically under-diagnosed condition, and most of those who have it – diagnosed or not – have at least one additional chronic condition. Detection of cognitive impairment at the earliest stage allows providers to establish the individual's and family's treatment preferences, connect them to community resources, and helps them to plan for the future. This type of planning can prevent confusion and stress for the patient and family, and allow for the best possible quality of their lives. Documenting a diagnosis can also aid in coordinating care, particularly around complex chronic conditions.

Seventy-four percent of people with Alzheimer's disease have at least one other chronic condition. Sixty-six percent have hypertension, thirty percent have heart disease, and twenty-nine percent have diabetes. The management of any chronic condition is challenging; such management in an individual with cognitive impairment is exponentially more difficult. These individuals are less likely – or are often unable – to comply with treatment recommendations and instructions, such as how and when to take medications, keep appointments with providers, and communicate pain or problems. These complications result in more hospitalizations, longer hospital stays, and higher costs than those with the same conditions who do not have Alzheimer's disease. This complex care requires detailed, coordinated care plans organized around the dementia diagnosis.

Once a diagnosis is established, providers can work with the individual and family to establish goals and a treatment plan with the understanding that the individual's dementia may require special measures to effectively treat the other chronic conditions. Providers, individuals, and families should work together to build a care team, accounting for all conditions. Moreover, providers should refer patients and families to appropriate support services, including enrolling in clinical trials. Participating in planning early in the disease process allows individuals with Alzheimer's to create advance directives regarding their care and finances – so that their wishes can be carried out when they are no longer cognitively able to make such decisions, and discuss advanced directives regarding their care and finances so that the patient's wishes can be honored when he or she is no longer cognitively capable of participating in decision making.

Alzheimer's disease also impacts the health and quality of life of those acting as caregivers. The physical and emotional impact of caregiving on Alzheimer's and other dementia caregivers costs an estimated \$9.3 billion annually in increased health costs specifically for the caregivers. Dementia caregivers are also more likely than caregivers of other older people to say that caregiving makes their health worse. Alzheimer's caregivers report higher rates of depression and stress as a result of their caregiving

responsibilities. The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions.

Caring for an individual with Alzheimer's also has a negative effect on employment, income and financial security. More than half of Alzheimer's and dementia caregivers who are employed full or part time report that their caregiving responsibilities cause them to go in late to work, leave work early or take time off. In addition, fifteen percent of Alzheimer's and dementia caregivers take a leave of absence from work, thirteen percent go from working full time to part time and nine percent give up working entirely because of their caregiving duties.

Alzheimer's also presents challenges for those facing the disease without a caregiver nearby or at all. One in seven individuals living with Alzheimer's – nearly 800,000 – live alone and as many as fifty percent do not have a formal caregiver. As a result, their deterioration isn't noticed. These individuals risk a late or missed diagnosis and are also more likely to wander off, fall, and even die compared with people with Alzheimer's who don't live alone. There are an estimated 2.3 million long-distance caregivers for individuals with Alzheimer's disease or a related dementia who live at least one hour away from the care recipient and about one in five long-distance caregivers is a primary caregiver. This makes coordinating the care of the individual with Alzheimer's far more difficult.

Conclusion

Thank you again for the opportunity to testify today. I appreciate the steadfast support of the Committee and its focus on improving chronic care. Alzheimer's is a disease that not only impacts the diagnosed person, but also the lives of their loved ones. I ask Congress to address the chronic care issues around Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act. The most recent update to the *National Plan to Address Alzheimer's Disease*, released in April 2014 by the U.S. Department of Health and Human Services, is starting that process by taking steps to identify and review measures of high quality dementia care in eight areas: 1) diagnosis, treatment, and care; 2) timeliness and accuracy of diagnostic evaluation; 3) patient and caregiver quality of life; 4) evaluation of behavioral symptoms and comorbid conditions; 5) care coordination; 6) assessment and management of caregiver burden; 7) training and provider knowledge; and 8) patient-centered outcomes and goals of care. This focus on quality dementia care will help individuals living with Alzheimer's disease and their caregivers across the country.

An epidemic is well upon us, and too many families are in situations like ours – facing a fatal brain disease that currently has no way to prevent, cure or even slow its progression and left without a support system to guide us. As a nation, we cannot afford to wait until Alzheimer's bankrupts the nation, just as it already has so many hardworking families in Oregon, Utah, and all across this country. We must make the smart investment now to realize a better, healthier future for our families and our nation. Thank you.