

United States Senate Committee on Finance  
Subcommittee on Health  
Alzheimer's Disease: The Struggle for Families, a Looming Crisis for Medicare

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Good afternoon, Chairman Toomey, Ranking Member Stabenow, and members of the Subcommittee. Thank you for this opportunity to address the issues associated with being a care partner for individuals living with Alzheimer's disease and other dementias.

More than 5 million Americans are living with Alzheimer's, and without significant action, as many as 16 million Americans will have Alzheimer's disease by 2050. More than 10,000 baby boomers a day will turn 65 and as these baby boomers age, one in eight will develop Alzheimer's. This explosive growth will cause Alzheimer's costs to Medicare and Medicaid to increase from \$160 billion today to \$735 billion in 2050 (in today's dollars) and threatens to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

It is an honor to represent the over 5 million Americans living with the disease and more than 15 million care partners who love them. Alzheimer's disease is not a respecter of role, rank, or relationship.

Those afflicted with Alzheimer's disease are adept at concealing their confusion, embarrassment, frustrations and fears, often before their partners begin to realize that there is a problem. This was certainly true in our case. The cues were subtle, and I had a demanding career. It wasn't until the notes were piling up, including cues on his hands, that I suggested we see someone to eliminate the big "A" fear.

On November 11, 2010, after some seemingly simplistic tests, we were told by Dr. Weisman that my Mark, a 70-year-old proud man, devoted husband and father, has Alzheimer's disease, a progressive, fatal disease of the brain. Based on those "simplistic" tests, we were told Mark was on the "bunny slope" -- we could expect a gradual decline. No direct diagnostic tests were available, and we were often told, "no one ever really knows until they are dead and you can see it in the brain." Painfully glib, but true. Mark was prescribed medication to try to extend his memory, and we were sent on our way stunned, reeling, and projecting scenarios we could never fully appreciate.

Following Dr. Weisman's diagnosis, Mark experienced depression, anxiety, and obsessive-compulsive behaviors that led me to look for a geriatric psychiatrist, not an easy specialist to find. I found someone who was compassionate and intelligent but untrained in dementia. She prescribed medication for Mark's symptoms, and at each session she give Mark a pep talk by saying "you are not typical Alzheimer's," an oxymoron that reinforced our hope and denial.

If Mark was not *typical Alzheimer's*, what *typically* was he, and was he receiving the right protocols? Another neurologist was recommended. In August 2015, we met with a clinical neuropsychologist for further testing. Mark endured six grueling hours of testing, including assessments of intellectual functioning, behavioral observations, visual and verbal capabilities, memory orientation, concentration

and working memory, verbal learning, language skills, motor and emotional functioning, and executive functioning. Following this battery of tests, Mark's driver's license was revoked, and Mark left the session feeling traumatized, frustrated, and "not typically" angry. The results indicated subcortical features, dementia appears to be present, mild-to-moderate in severity. However, the "precise nature" of Mark's dementia was "unclear" from the test data alone. We went back to the referring neurologist who, with a dismissive wave of his hand, declared that he didn't agree with the diagnosis and that was all he could do.

We went back to Dr. Weisman, who was clearly disturbed with what Mark went through. Knowing Mark's scientific curiosity, he suggested a clinical trial - the Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study. The IDEAS Study will determine the clinical usefulness on patient-oriented outcomes of a brain PET scan that detects amyloid plaques, a core feature of Alzheimer's disease. This study is particularly helpful in determining a diagnosis for people like Mark who do not present with typical dementia or cognitive decline. After our previous experience, it was so reassuring to know that there are doctors who care enough to help us pursue a confirmed diagnosis and understand how important this really is.

When Mark had the PET scan that confirmed his diagnosis, all of the debate, searching, and uncertainty was put to rest and the real work of living with the disease began. Mark is willing to engage in other trials and wants to donate his body when he dies. It is his desire to salvage something good from the nightmare of watching the disintegration of his mind and life.

We joined an Alzheimer's Association support group where we shared knowledge and survival skills. Issues for care partners have included: our children's distrust based on fear; how to get rid of guns; stealth banking; thermostat wars; repetition, the date, family information, media, etc.; hunger strikes; isolation; support; grieving; and survivor guilt. We established a Durable Power Of Attorney, Medical Directives, wills, financial planning, medical equipment, shoes for his gait, bathing, diet, weight loss, and family/friends engagement.

For me, coping means trying to stay present, with him, in his space as long as his mind allows me. The rate of stress and depression has been described as "unique" to caregivers. Everyone says "it's hard" and that is the simple truth. The awareness that self care of my mind, body, and spirit is critical to survival is growing faster than the resources to make it a reality.

Adult Day Care two days a week for my husband, and me, is expensive and I know the costs will increase over time. My husband thought he was preparing to leave his family some financial security that will melt like the snow in spring. However, I am also concerned for those homeless, poor and working poor, who lack transportation and childcare let alone eldercare. Without knowledge, health care and case management resources, families living in the margins of our society cannot hope to manage the daily demands of those afflicted with Alzheimer's disease. Investment in Alzheimer services can prevent the terrible social and fiscal costs in social services due to the dissolution of families.

Before Mark enrolled in the IDEAS Study and was able to get an accurate diagnosis, I was asked, “what difference would a precise diagnosis make?” A fair question since we know at this moment there is no cure. Trying to express this isn’t easy:

I looked up the quote “Better the devil you know (than the devil you don’t).” This is said when you think it is wiser to deal with someone or something familiar, although you do not like him, her, or it, than to deal with someone or something you do not know that might be worse.

I believe there is power in *naming*, how can we cure something if we don’t even know its name?

On a practical level, an early and accurate diagnosis of Alzheimer’s disease affords the individual the opportunity, dignity, and respect of participation and involvement in financial and legal decisions with his or her family. Legislation like the HOPE for Alzheimer’s Act, which allows individuals newly diagnosed with Alzheimer’s disease or a related dementia to have a care planning session with a health care provider, would do just that. If HOPE had been around at the time of Mark’s diagnosis, I am certain that we would have felt much less alone in this fight.

Of the more than 5 million American seniors currently living with Alzheimer’s disease or another dementia, only 33 percent are aware of the diagnosis. Studies show that one of the reasons doctors do not disclose an Alzheimer’s diagnosis is insufficient time and resources to provide support to patients and caregivers at the time of diagnosis. The HOPE for Alzheimer’s Act works by incentivizing health care practitioners to: (1) dedicate time and resources to fully inform a beneficiary about the diagnosis; (2) have a meaningful discussion of treatment and support options; (3) develop a care plan specific to the beneficiary, accounting for all other conditions; and (4) document the diagnosis and care plan in the patient’s medical record that is shared with all providers treating the individual.

Following a diagnosis, care planning is crucial to improving outcomes, maintaining quality of life, controlling costs and planning appropriately for the future. The HOPE for Alzheimer’s Act builds on existing Medicare coverage of a diagnosis to provide individuals with Alzheimer’s and their caregivers comprehensive care planning services, including information on medical and non-medical options for ongoing treatment, services, and supports. The HOPE for Alzheimer’s Act would also allow the care planning discussion to occur with or without the beneficiary present, allowing for the facilitation of more effective communication between the health care provider and the beneficiary’s family, caregivers, or personal representative.

Additionally, the HOPE for Alzheimer’s Act ensures documentation of a diagnosis and the care plan in the beneficiary’s medical record. Although Medicare requires documentation of a diagnosis for purposes of reimbursement, there is no requirement for a diagnosis to be documented within an individual’s medical record. Documentation is critical to ensuring effective management of comorbidities (such as heart disease and diabetes) by an individual’s care team and allows for care coordination among treating physicians.

Finally, by requiring a provider outreach campaign upon implementation, the HOPE for Alzheimer’s Act also helps ensure beneficiaries have access to these services by educating appropriate providers about the

benefit and its elements. The HOPE for Alzheimer's Act is also consistent with the *National Plan to Address Alzheimer's Disease*, which calls for educating health care providers as well as supporting individuals and families upon diagnosis to prepare for care needs.

The HOPE for Alzheimer's Act may also work to reduce the disparity between costs for Medicare beneficiaries with Alzheimer's disease and those without. More than 85 percent of people with Alzheimer's and other dementias have other comorbid chronic conditions, and they are about 4 times more likely to have six or more chronic conditions, adding to the complexity of their care. Consequently, hospitalization rates are twice as high and costs are nearly three times as high for Medicare beneficiaries with Alzheimer's compared with other beneficiaries. A recent analysis of the HOPE for Alzheimer's Act by Healthsperien, which is comprised of former CBO staff, revealed that this legislation would lead to reductions in hospitalizations and emergency room use as well as improved management of comorbid chronic conditions and better management of medications for those receiving the benefit. As a result of the legislation, net federal health spending would decrease by \$692 million over a ten-year period.

Until a scientific breakthrough leads to an effective treatment or cure for Alzheimer's disease, we must work to improve the Medicare system to provide better care for American families facing this diagnosis. The HOPE for Alzheimer's Act is a win-win: it will improve the quality of care and quality of life for Medicare beneficiaries and families facing Alzheimer's disease, while reducing Medicare utilization and spending for those who receive the benefit.

Thank you again for the honor and opportunity to testify today. I hope that I have been able to address the issues of caregivers and their loved ones with the respect and recognition they deserve. More importantly, I hope my message conveyed to you the exact nature of the problem through our eyes and perhaps has given you some insights on how your leadership could be instrumental in the current and future needs of our families and communities.