

Senate Committee on Finance

Alzheimer's Awareness: Barriers to Diagnosis, Treatment and Care Coordination
2:00 pm, 215 Dirksen Senate Office Building

Purpose

The purpose of this hearing was to discuss barriers to efficient Alzheimer's diagnosis, treatment and care coordination, as well as the burden placed on caregivers and families.

Members Present

Chairman Toomey, Ranking member Stabenow, Senator Cassidy, Roberts, Menendez, Casey, Whitehouse, Cardin, Carper, Lankford, Daines, and Brown

Witnesses

Jason Karlawish, MD., Professor of Medicine, Medical Ethics and Health Policy, and Neurology, and Co-Director, Penn Memory Center, University of Pennsylvania Philadelphia, PA

Janet Tomcavage., Chief Nursing Executive, Geisinger, Winfield,, PA

Marc A. Cohen, Ph.D., Professor, Department Of Gerontology, Co-Director, Leading Age LTSS Center, and Research Director, Center For Consumer Engagement in Health Innovation UMass Boston and Community Catalyst, Newton, MA

Lauren Kovach., Alzheimer's Advocate, Brighton, MI

Opening Statements

Chairman Toomey said that the burden Alzheimer's places on patients, caregivers and families puts it in a league of its own. Nearly one in 10 seniors is living with Alzheimer's disease. In 2019 alone, this disease and other memory disorders is likely to cost over \$290 billion in health care costs and long-term services. A majority of these costs fall on the Medicare and Medicaid program. Unfortunately, there is no cure for Alzheimer's and progress has been very slow. Despite massive investments, patients with Alzheimer's are left with little treatment options and struggle to afford long-term health care. Furthermore, Medicare and Medicaid do not provide enough relief to beneficiaries seeking long-term care. Together, Congress can work on a bipartisan basis to tackle the challenges raised today.

Ranking Member Stabenow said that this is not about the numbers, it is about people's lives. Alzheimer's steals loved ones from their family one memory at a time. While investment and research related to Alzheimer's has grown significantly in recent years, the progress that has been made is not enough. Not only does Congress need to incentivize a cure, there is also a need to empower caregivers and family members with more support and resources. The Improving Hope for Alzheimer's Act has been introduced and there is a strong bipartisan path forward. There are several other bills that will encourage higher quality in Alzheimer's care and improving coordinated services.

Testimony

Dr. Karlawish said that a typical patient experience at Penn Memory Center begins with a story of anguish and confusion from family members trying to find answers. In order to

make a diagnosis of Alzheimer's, a provider typically needs around 60 minutes and at least one interview with a family member or loved one. After this, there is a follow up visit and from there the patient is referred to a social worker. The Penn Memory Center is able to do this because it benefits from subsidies from both research and philanthropy. Unfortunately, there is a shortage of providers equipped to serve this diverse population. The best thing that Congress can do to is to create a health care market that encourages providers to treat Alzheimer's patients.

Ms. Tomcavage said that a lack of education and understanding is one of the biggest barriers to Alzheimer's care. Furthermore, there is a sense of complacency in the medical community that often delays administering care. It is time to treat Alzheimer's like a public health problem akin to the opioid crisis. There need to be large investments in at home tele-health to help connect patients with care who may have structural barriers to accessing typical care. It is also true that payments to non-health care providers are also critical to allowing individuals to age with dignity in their own home.

Dr. Cohen said that this challenge is far too large for only the private or public market to try to solve it alone. Making private insurance more accessible means making it more affordable and attractive to consumers. While private insurance can play an important role going forward, the role of public insurance is arguably more important. Most middle income Americans are not poor enough to qualify for Medicaid until they spend down their savings. Furthermore, many middle class individuals are priced out of the insurance market. This is unfortunate because long-term care insurance has tremendous value. There are a number of solutions to this issue including changing tax structures and insurance requirements. Long-term care offers should be sold to Medicare and Medicare Advantage as well as sold on the exchange. It is beneficial to everyone if more people have purchased long-term care insurance.

Ms. Kovach said that her life took an unexpected turn when her grandmother was diagnosed with Alzheimer's. At this point Ms. Kovach had to withdraw from college and along with her mother become a full time caregiver. Unfortunately there were no resources to help them transition into becoming a full time caregiver. They were left on their own. Since this diagnosis, Congress has made significant steps in improving access to Alzheimer's care. However, even today most Alzheimer patients do not have access to care planning services, leaving them and their caregivers to figure it out on their own. Alzheimer's research needs to be encouraged and Congress should pass the Improving HOPE for Alzheimer's Act.

Questions and Answer

Chairman Toomey asked if allowing families to use retirement dollars to buy tax-free long-term care insurance would help families. **Dr. Cohen** said this would help families with retirement plans. **Chairman Toomey** asked if this plan would reduce premiums due to attracting a larger risk pool. **Dr. Cohen** said yes.

Ranking Member Stabenow asked how care planning services would have helped Ms. Kovach. **Ms. Kovach** said this it would have provided her access to many resources that she did not know were available at the time. There would have been less of a burden placed on the family. **Ranking Member Stabenow** asked how to make high quality care the norm as opposed to the exception. **Dr. Karlawish** said that there needs to be a business model that supports and sustains high quality Alzheimer's care. Physicians need to be reimbursed appropriately.

Sen. Cassidy asked if it is true that increasing investments in Alzheimer's research will not lead to much progress. **Dr. Karlawish** said no. **Sen. Cassidy** asked if more dollars for research would be helpful. **Dr. Karlawish** said yes. **Sen. Cassidy** asked if Medicare Advantage plans are structured appropriately to reimburse providers. **Ms. Tomcavage** said plans that used value based payments are the best. **Sen. Cassidy** asked why health saving accounts are not enough. **Dr. Cohen** said the data speaks for itself, not enough people use them. **Sen. Cassidy** asked if telehealth is an appropriate solution. **Dr. Karlawish** said that follow up visits should be done over tele communication devices but the initial diagnosis should be delivered in person.

Sen. Roberts asked if caregivers need to be helped as much as providers. **Dr. Karlawish** said yes, it is a full time job.

Sen. Menendez asked if America has the clinical workforce to address the burden of Alzheimer's. **Dr. Karlawish** said no. **Sen. Menendez** asked why such large disparities exist among racial groups surrounding the prevalence of Alzheimer's. **Dr. Karlawish** said it is often tied to social and economic access. A life of poverty often leads to worse health outcomes that can compound on each other.

Sen. Casey asked what impact cuts to Medicaid would have on people with Alzheimer's. **Dr. Cohen** said that it would be detrimental. **Sen. Casey** asked if there is a connection between hearing loss and dementia. **Dr. Karlawish** said yes. Hearing loss is an identifiable risk factor for dementia.

Sen. Whitehouse asked why there should be reason for optimism surrounding Alzheimer's. **Dr. Karlawish** said the fact that there is a Senate hearing on Alzheimer's is encouraging. There has also been tremendous progress made since 1976 in understanding the biology and pathology of the disease.

Sen. Cardin asked if protocols in primary care should be more aggressive in diagnosing Alzheimer's. **Dr. Karlawish** said Congress needs to provide a reliable business model to encourage providers to aggressively diagnose and treat the disease. **Sen. Cardin** asked if we need to figure out better ways to treat those who have been diagnosed early. **Dr. Karlawish** said yes. **Sen. Cardin** asked how to get there. **Dr. Karlawish** said there is a need for more research and a need to anticipate the health system.

Sen. Carper asked if mind stimulating activities can help prevent Alzheimer's. **Ms. Kovach** said she does not know. **Dr. Cohen** said that the research suggests it may prevent Alzheimer's. **Ms. Tomcavage** said yes, and drugs also play a role. **Dr. Karlawish** said yes. **Sen. Carper** asked if it is possible to train primary care providers and nurses to administer Alzheimer's care. **Dr. Karlawish** said yes.

Sen. Lankford asked what other countries are investing in Alzheimer's research. **Dr. Karlawish** said Europe and Japan have made substantial investments. **Sen. Lankford** asked if there is coordination between the US, Europe and Japan. **Dr. Karlawish** said yes. **Sen. Lankford** asked what barriers to care coordination exist. **Ms. Tomcavage** said the amount of funding at the local level is not uniform. Additionally, there is a lack of awareness surrounding available resources. Finally, there is not enough anticipation around Alzheimer's.

Sen. Daines asked about the benefits of care planning. **Dr. Karlawish** said that care planning allows family members and patients to figure out the best path forward and live a predictable and consistent life. It also produces better health outcomes. **Sen. Daines** asked why it is important to improve early diagnosis. **Dr. Karlawish** said that health outcomes are better when there is early diagnosis.

Sen. Brown asked what provisions in the ACA have improved Alzheimer's care. **Dr. Karlawish** said many caregivers have to leave the workforce, so the ACA is able to provide insurance to this population. Care coordination has also been possible due to CMMI, which was created by the ACA. **Sen. Brown** asked how Congress can better support families. **Ms. Kovach** said paid family leave for caregivers would be very helpful.