



ALZHEIMER'S FOUNDATION OF AMERICA

STATEMENT TO

**THE SENATE FINANCE SUBCOMMITTEE ON
HEALTH**

**HEARING ON ALZHEIMER'S AWARENESS:
BARRIERS TO DIAGNOSIS, TREATMENT AND CARE
COORDINATION**

NOVEMBER 20, 2019

Chairman Toomey, Ranking Member Stabenow and Members of the Senate Finance Subcommittee on Health:

On behalf of the Alzheimer's Foundation of America (AFA), a nonprofit organization whose mission is to provide support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide, and fund research for better treatment and a cure, we commend the Subcommittee for honoring National Alzheimer's Awareness Month by holding this hearing on Alzheimer's disease to raise awareness and highlight obstacles in diagnosis, treatment and care that impacts the quality of life for the millions of American families who live with dementia.

Alzheimer's Disease and Its Impact

Alzheimer's disease is the sixth leading cause of death in the US¹ and the only cause of death in the top 10 with no cure or treatment to reverse or slow its progression. It is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. As our population ages, incidences of the number of persons affected by this insidious brain disorder are expected to double by 2060 according to the Centers for Disease Control and Prevention (CDC).²

Individuals with Alzheimer's disease use a disproportionate amount of health care resources; for instance, they are hospitalized two to three times as often as people the same age who do not have the disease.³ Similarly, nearly half of all nursing home residents have Alzheimer's disease.⁴

Overall, health costs for persons with dementia are substantially larger than those for other diseases, and many of the expenses are not covered by private or public health insurance

¹ While the Centers for Disease Control and Prevention (CDC) lists Alzheimer's disease as the sixth leading cause of death in the US (see, www.cdc.gov/nchs/fastats/leading-causes-of-death.htm), recent studies cite that over 500,000 Americans a year die as a result of dementia, making Alzheimer's disease the third leading cause of death in the US. See, Contribution of Alzheimer disease to mortality in the United States, James, Bryan Ph.D. et. al., *Neurology* (March 5, 2014) (www.neurology.org/content/early/2014/03/05/WNL.0000000000000240).

² Matthews, Kevin A. et al., Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged ≥65 years, *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, Volume 15, Issue 1, 17 – 24 (2018).

³ CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011 (www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).

⁴ See, Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia, AHRQ Publication No. 12(13)-EHC127-EF (www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050127/) (approximately 45-67% of all nursing home residents have dementia).

programs.⁵ This places a large financial burden on families, and these burdens are particularly pronounced among the demographic groups that are least prepared for financial risk.⁶

In addition to costs of care, there's an additional human toll. For each person with Alzheimer's disease, there are multiple caregivers who respond to 24/7 needs related to activities of daily living. Caregiving duties often fall on family members who are overwhelmed both emotionally and physically, and whose health and well-being often suffer as they fulfill this role.⁷ There is a higher incidence of sickness and mortality among Alzheimer's disease caregivers, compared to other caregivers.⁸ In 2011, family caregivers provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over \$210 billion.⁹

Finally, there is no drug or modifying treatment to stop or slow the progression of dementia. Four decades of intense research efforts have failed to yield any effective pharmaceutical interventions for Alzheimer's disease with a clinical trial failure rate of nearly 99.6% (compared to a 20% success rate for cancer drugs).¹⁰

Barriers to Diagnosis

Several barriers remain in place that make it difficult for physicians to diagnose dementia. A study examining the literature around these obstacles identified six common themes¹¹ including lack of support for patients, caregivers, and physicians, time and financial constraints, stigma, diagnostic uncertainty, and concerns around disclosure of the diagnosis.¹² Further, a 2006 editorial in the Journal of the American Geriatric Society estimated that missed diagnoses are greater than 25 percent of the dementia cases and may be as high as 90 percent.

Accurate and timely diagnosis can provide greater opportunities for people with Alzheimer's disease to participate in clinical trials. New drug therapies currently being tested focus on stopping progression in the early stages of the disease, requiring trial participants to have low to

⁵ Kelley AS, McGarry K, Gorges R, et al. The Burden of Health Care Costs for Patients with Dementia in the Last 5 Years of Life. *Ann Intern Med.* 2015;163:729–736 (27 October 2015) (<https://doi.org/10.7326/M15-0381>).

⁶ See, Kelley AS, *ibid.* “Average total cost per decedent with dementia (\$287,038) was significantly greater than that of those who died of heart disease (\$175,136), cancer (\$173,383), or other causes (\$197,286) ($P < 0.001$). Although Medicare expenditures were similar across groups, average out-of-pocket spending for patients with dementia (\$61,522) was 81% higher than that for patients without dementia (\$34,068); a similar pattern held for informal care.”

⁷ CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011.

⁸ *Ibid.*

⁹ A. Stevens, PhD., Next Steps in Family Caregiving Research: Interventions Designed for Impact (www.nia.nih.gov/sites/default/files/alan_stevens_0.pdf).

¹⁰ Z.S. Khachaturian, PhD, 40 Years of Alzheimer's Research Failure: Now What?, *MedPage Today* (September 13, 2018) (<https://www.medpagetoday.com/neurology/alzheimersdisease/75075>).

¹¹ D. Judge, J. Roberts, R. Khandker, (et. al.), Physician Perceptions about the Barriers to Prompt Diagnosis of Mild Cognitive Impairment and Alzheimer's Disease, *International Journal of Alzheimer's Disease*, vol. 2019, Article ID 3637954, 6 pages, 2019. <https://doi.org/10.1155/2019/3637954>.

¹² *Id.*

mild cognitive impairment. Cognitive screening can help identify this pre-symptomatic population who will be essential to accelerate promising drug development.

Early detection will allow individuals to adopt prevention strategies that help slow or plateau progression of dementia.¹³ Lifestyle activities like increasing aerobic exercise, maintaining a “Mediterranean” diet, controlling hypertension and engaging in cognitive “brain” games have been shown to decrease cognitive decline and dementia by increasing an individual’s cognitive reserves.¹⁴

Given the obstacles to early detection, a simple, inexpensive and non-invasive cognitive screening should be promoted and encouraged. AFA recommends that Congress expand memory screening efforts and promote the benefits of memory screening and early detection of Alzheimer’s disease. To accomplish this, we urge Congress to:

- Fund the BOLD Act initiatives at CDC which will go to increasing education of public health officials, health care professionals and the public on Alzheimer’s, brain health and cognitive health disparities.
- Increase physician and public awareness of Medicare’s annual wellness visit and its cognitive screen component, as well as its reimbursement.
- Incentivize private insurers to reimburse health professionals for conducting cognitive screens of older Americans or those who have a genetic link - or other predisposition (i.e., play contact sports) - for dementia.

Barriers to Treatment

In 2012, Congress approved the National Plan to Address Alzheimer’s Disease which sets a goal for preventing and effectively treating Alzheimer’s disease by 2025. AFA is grateful that Congress, in the past several budget cycles, has honored this commitment by approving historic increases in federal funding for clinical research into a cure for Alzheimer’s disease. Appropriations for the National Institute on Aging (NIA), the nation’s leading federal funder of Alzheimer’s disease research, has increased from just over a billion dollars in 2012, to over three billion in fiscal year 2019.

This influx in funding has allowed NIA to fund new and innovative targets in the hopes of finding a cure. These new targets include inflammation, tau proteins, neurotransmitters, genetics, hypertension and growth hormones to name a few. Failure to provide such an investment will leave promising research unfunded and further increase the timeline to get us to a cure or modifying treatment.

¹³ Crous-Bou M, Minguillón C, Gramunt N, Molinuevo JL. Alzheimer's disease prevention: from risk factors to early intervention. *Alzheimers Res Ther.* 2017;9(1):71. Published 2017 Sep 12. doi:10.1186/s13195-017-0297-z

¹⁴ Stern Y. Cognitive reserve in ageing and Alzheimer’s disease. *Lancet Neurol.* 2012;11(11):1006–12.

In addition to funding, the lack of an Alzheimer's disease infrastructure will pose as a barrier to treatment should one or more therapies become available. A substantial number of existing cases with mild cognitive impairment (MCI) would have to be screened, diagnosed, and then potentially treated as quickly as possible when a therapy first comes to market, in order to prevent progression to Alzheimer's.

A 2018 study found the infrastructure for Alzheimer's disease to be lacking and that the US health system was unprepared and currently insufficient to handle the expected caseload if there was a cure.¹⁵ According to the study, the most pressing constraint is limited capacity of specialists to evaluate and diagnose patients, but access to imaging to confirm Alzheimer's disease and to infusion centers to deliver the treatment would also contribute to waiting times.¹⁶

To alleviate these barriers to treatment, AFA recommends that Congress:

- Continue robust investment into research of dementia at the National Institute of Aging (NIA) and other federal health agencies.
- Invest in Alzheimer's disease infrastructure which includes promotion and expansion of a geriatric workforce, increased awareness of brain health and access to imaging and other tools to aid in diagnosis and treatment.

Barriers to Care Coordination

Caring for a loved one with Alzheimer's disease or a related dementia poses enormous and life-changing challenges for families and caregivers. Person-centered, coordinated care delivery models and smart investments in supports and training will extend limited resources by lowering overall costs of care for a person with Alzheimer's disease. Coordinated care delivery that avoids unnecessary hospitalizations and provides tools to care partners that can delay nursing home placement are necessary policy changes that will allow Americans to provide quality care until such time as clinical research discovers a cure or effective treatment for this fatal brain disorder.

According to an AARP study, despite a growing evidence that person-based coordinated care models coupled with dementia caregiver supportive services are effective, few of these care models have been implemented into everyday practice.¹⁷

AFA urges Congress to call on federal health programs to fully adopt person centered care coordination models and caregiver support programs, including:

¹⁵ Liu, Jodi L., Jakub P. et. al., Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment, RAND Corporation, 2017 (www.rand.org/pubs/research_reports/RR2272.html).

¹⁶ *Ibid.*

¹⁷ AARP Public Policy Institute, From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia (September, 2017) (www.aarp.org/ppi/info-2017/from-research-to-standard-practice.html).

- Medical homes for persons living with dementia - Medical homes deliver care that is coordinated, comprehensive, efficient and personalized. Practitioners manage all aspects of care, not just treatment.¹⁸ Coordinated care prevents unnecessary services and reduces overall health care costs by targeting the precise needs of the person.
- Independence at Home (IAH) - The IAH model uses primary care teams led by physicians or nurse practitioners to deliver timely, in-home primary care to Medicare beneficiaries with multiple chronic illnesses and functional impairments, including those living with dementia.
- Program of All-Inclusive Care for the Elderly (PACE) - PACE focuses only on seniors, who are frail enough to meet their State's standards for nursing home care. PACE features medical and social services that can be provided at an adult day health center, home, or inpatient facility. For most people, the service package allows them to continue living at home while receiving services.
- The REACH VA Program – is designed to assist caregivers with challenges such as self-care; problem solving; mood management; asking for help; and stress management. Caregivers are matched with a trained and certified REACH VA Program Coach who provides individual sessions where the caregiver receives support, training and best practices.

AFA appreciates the opportunity to provide some recommendations that could help overcome the current barriers to the diagnosis, treatment and care coordination of Alzheimer's disease. AFA stands ready to assist you and the Committee in any way to advance these and other proposals that will provide optimal care, while creating efficiencies that lower costs of care without compromising access or quality. Feel free to contact Eric Sokol, AFA's senior vice president of public policy at: esokol@alzfdn.org if you have any questions or need further information.

¹⁸ The Patient-Centered Primary Care Collaborative, Joint Principles of the Patient-Centered Medical Home (Feb. 2007).