

February 11, 2020

## **SENATE FINANCE SUBCOMMITTEE ON HEALTH CARE SEEKS FEEDBACK ON ACTIONS TO ADDRESS ALZHEIMER'S DISEASE**

Alzheimer's disease is the most common form of dementia, affecting an estimated 5.8 million Americans.<sup>1</sup> Without effective treatment options or a cure, patients are powerless to slow the progression of Alzheimer's disease as it robs them of their memory, mental faculty, and independence. Friends and family devote countless hours each year to care for loved ones suffering with the illness.

The economic costs are also staggering, and much of the burden falls on federal health care programs. In 2019, Alzheimer's disease and related memory disorders cost an estimated \$290 billion in health care, long-term care, and hospice expenses, two-thirds of which will be borne by Medicare and Medicaid.<sup>2</sup> As the number of Americans living with Alzheimer's disease grows to nearly 14 million by 2050, annual health care expenditures attributable to the disease will balloon to \$1.1 trillion.<sup>3</sup>

The daunting challenges associated with the disease were presented at a Senate Finance Subcommittee on Health Care [hearing](#) held on November 20, 2019. In addition, members of the Senate Finance Committee and the Bipartisan Congressional Task Force on Alzheimer's invited key staff from the Department of Health and Human Services to brief them on the status of the *National Alzheimer's Project Act* (Public Law 111-375). We all share the goal of discovering an effective treatment by 2025 but, as highlighted in the hearing, more can be done in the meantime to improve the care and quality of life for patients and families.

As such, the Senate Finance Subcommittee on Health Care is requesting feedback and suggested policy solutions from stakeholders – providers, researchers, patient advocacy groups, states, and others – to inform the development of potential future legislation. Areas of particular interest, building on what we have learned from the administration and legislative hearing, are outlined below. Comments may be submitted to [ALZFeedback@toomey.senate.gov](mailto:ALZFeedback@toomey.senate.gov) by March 13, 2020. We ask that stakeholders submitting policy recommendations include a brief background, along with any specific regulatory or statutory changes that may be required and relevant estimate of cost or savings to the federal government, if applicable.

### **Care Coordination in Federal Health Care Programs:**

- **Dually Eligible Beneficiaries:** The subcommittee seeks input on how best to increase care coordination efforts for individuals with Alzheimer's and related dementias in federally-funded programs that care for dual eligible beneficiaries, such as the Programs of All-Inclusive Care for the Elderly (PACE), Medicare Fee-for-Service, Medicaid, and under the Financial Alignment duals demonstrations. Additionally, we are seeking feedback on

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<sup>1</sup> <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

successes, challenges, and opportunities to improve the quality of care these programs provide.

- **Medicare Advantage Benefits:** Patients with Alzheimer's have unique needs, requiring a comprehensive set of benefits to improve the quality of care. Medicare Advantage plans have recently been authorized to offer supplemental services, such as transportation, adult day care, meal delivery, and home and community based services. The subcommittee is interested in understanding how these services have impacted Alzheimer's patients and exploring challenges and opportunities to further serve these beneficiaries. The subcommittee also seeks feedback on what the traditional Medicare program should cover in order to better serve individuals with Alzheimer's.
- **Special Needs Plans (SNPs):** SNPs have recently been permanently authorized and are afforded considerable flexibilities to better coordinate care for more complex populations with chronic care needs. We are seeking feedback as to how these plans manage care for enrollees with Alzheimer's disease compared to traditional Medicare Advantage plans and if additional flexibility is needed to improve care coordination and quality.
- **Medicare Coverage of Care Planning Services:** Dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. In 2017, CMS implemented a new Medicare benefit (CPT code 99483) based on the bipartisan HOPE for Alzheimer's Act. Uptake of the code has been slow. We are seeking feedback on how to improve access to comprehensive care planning services for individuals with Alzheimer's and related dementias.
- **Home and Community Based Services:** The Older Americans Act focuses on delivering home and community based programs and supports, including nutritional programs, in-home services, transportation, elder abuse prevention, legal services, and caregiver support. OAA services are targeted at older individuals who have the greatest economic and social need, have low income, are members of low-income minority groups, reside in rural areas, have limited English proficiency, or are at risk of entering a nursing home. We are seeking feedback on how the programs are reaching individuals living with Alzheimer's and other dementias and any gaps that may exist in these services.

### **Improving Detection and Care:**

- **Ensuring Early Detection and Diagnosis:** Connecting Alzheimer's patients with options to address symptoms, and someday, treatments and a cure, requires early detection and a diagnosis documented in an individual's medical record. While National Institute on Aging at NIH has validated tests to detect cognitive impairment, we understand there is wide variation on the use of these tools and other evidence-based practices. We seek feedback on how to better utilize the existing "Welcome to Medicare" initial exam and Medicare annual wellness visits to screen, detect, and diagnose Alzheimer's. We also seek feedback on how best to incentivize detection and high quality care.

### **Improving Access and Affordability to Long-Term Care Coverage:**

- **Long Term Care Coverage:** The cost of long-term care services can have a crippling effect on families and one's retirement savings. Long-term care insurance is a way to mitigate this cost by insuring against the risk of a long-term care event. We seek feedback on the share of

patients receiving long-term care benefits pursuant to long-term care insurance, the share of patients paying for these services out of pocket, and the share of patients receiving benefits under Medicaid. We also seek feedback on the premium cost of long-term care insurance policies, and how various forms and features of the insurance policy impact the price. Lastly, we seek feedback on the extent to which traditional health insurance meets the needs of patients with terminal diseases that require home health care services.

### **Protecting Vulnerable Patients:**

- **Preventing Abuse:** While the vast majority of nursing homes, home health agencies, and hospices have dedicated leadership and staff committed to the health, wellness, and dignity of their residents, we cannot ignore reports of patient abuse<sup>4,5,6,7</sup>. The subcommittee is requesting policy recommendations that improve the oversight of facilities and providers with poor records of patient abuse, neglect, and safety without imposing undue burden on those that provide high quality care.

### **Encouraging Innovation:**

- **Investing in a Cure:** Billions of dollars have been invested into Alzheimer's disease research with the goal of developing an effective treatment, and ultimately, a cure. The subcommittee is seeking policy proposals that support research and development in innovative cures and policies that will reduce barriers and increase access to future innovative treatments and cures, while ensuring they remain affordable to patients and taxpayers.

We look forward to reviewing stakeholder feedback and working on bipartisan solutions that make meaningful improvements to the detection, education, treatment, and support for patients and families affected by Alzheimer's disease and related dementias.

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<sup>4</sup> <https://www.washingtonpost.com/health/2019/10/14/elderly-care-staff-accused-pitting-residents-against-each-other-dementia-fight-club/>

<sup>5</sup> <https://www.washingtonpost.com/news/morning-mix/wp/2017/01/28/a-family-suspected-a-caregiver-was-abusing-an-alzheimers-patient-so-they-installed-a-camera/>

<sup>6</sup> <https://www.floridatoday.com/story/news/crime/2019/04/09/man-molested-melbourne-nursing-home-nurses-aide-police-said/3409904002/>

<sup>7</sup> <https://www.gao.gov/products/GAO-20-10>