



Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States Senate Special Committee on Aging Hearing "Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies"

June 15, 2023

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing "Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Alzheimer's Impact Movement is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

An estimated 6.7 million Americans age 65 and older are living with Alzheimer's dementia in 2023. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$345 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$222 billion – or 64 percent – while out-of-pocket spending is expected to be \$87 billion. Total payments for health care, long-term care, and hospice care for people living with dementia are projected to increase to nearly \$1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

When coordinating public health emergency preparedness and response activities, it is critical to take into account the unique needs of individuals living with Alzheimer's and other dementia. We encourage the Committee to consider the following recommendations to expand and better support the public health infrastructure providing care for individuals living with Alzheimer's and other dementia before, during, and after public health emergencies.

Improved Response Coordination

While there is a need for greater coordination between federal, state, and local officials, there must also be clear lines of responsibility between federal, state, and local offices during public health emergencies. Congress must clarify who is in charge and these roles and responsibilities must be clearly communicated to states and local governments so they can include this information in their own preparedness planning.

The Alzheimer's Association and AIM recommend that each state designate one specific point person on long-term care issues to liaise with the federal government in times of crisis. Oversight for separate long-term care settings falls to different federal and state agencies which can make it difficult to coordinate efficiently during a public health emergency. If states were to establish one long-term care point person in charge of communicating with the federal government during times of crises, it would lead to a more coordinated, tailored response in long-term care communities.

Improved federal and state response coordination would also help ensure sufficient stockpiling and equitable distribution chains of essential testing, personal protective equipment, and vaccines, when available. These supplies and distribution chains should also include caregivers and home- and community-based care providers.

Public Health Preparedness and Response

Public health professionals play a critical role in minimizing the negative impacts of public health emergencies. Public health officials are able to tailor the federal, state, and local response in order to address the special vulnerabilities of people living with Alzheimer's and their caregivers. During a pandemic, this not only saves lives but also protects the larger community and may reduce strain on health care systems.

The Alzheimer's Association and AIM recommend that each state public health department have an internal expert with deep knowledge of the unique needs of people living with Alzheimer's and other dementia. The lack of a senior career staff director with expertise in Alzheimer's and other dementia in many state public health departments has affected the ability of those departments to effectively tailor the COVID-19 emergency response for those with cognitive impairment.

To help ensure that local and state preparedness and response plans address the particular vulnerabilities of people living with dementia, public health agencies must elicit insights from people living with dementia, caregivers, and experts on cognitive impairment. Further, emergency responders and shelter staff benefit from specific training about the signs and symptoms of dementia and other cognitive impairments.

We also recommend that the Centers for Disease Control and Prevention ensure there is a full-time gerontologist or geriatrician within the Infectious Disease National Centers who is able to liaise on emergency preparedness and response. This will help ensure readiness in how to

respond to the unique needs of seniors and people with Alzheimer's and other dementia when a new threat arises.

Access to Telehealth

Emergencies, disasters, and crises can result in difficult care transitions — moving from one location of care to another — for people living with dementia, especially due to evacuations or hospitalizations. The Alzheimer's Association and AIM also support continued access to telehealth. As noted above, Medicare beneficiaries with Alzheimer's and other dementias are more likely than those without dementia to have other chronic conditions. While 26 percent of Medicare beneficiaries age 65 and older with Alzheimer's and other dementias have five or more chronic conditions, only 4 percent of Medicare beneficiaries without dementia have five or more chronic conditions.

Most people with dementia also develop at least one dementia-related behavior like hallucinations and aggression, and a significant percentage of these individuals have serious associated clinical implications. Improved access to virtual and telehealth services allow persons with dementia to avoid unnecessary visits or travel that could further compromise their physical health, and also provide strained caregivers help managing medical needs or behaviors in the home.

The Alzheimer's Association and AIM also supported the expansion of Medicare and Medicaid coverage for certain telehealth services in response to the COVID-19 pandemic. The Centers for Medicare & Medicaid Services (CMS) temporarily expanded coverage for numerous codes that are beneficial to people living with Alzheimer's and other dementia, and we appreciate the flexibilities CMS implemented to reduce the risk of beneficiaries' exposure to the virus and ensure regular access to quality care. We encourage CMS to evaluate the effectiveness of these temporary codes, to the extent possible, during future public health emergencies to determine whether some are appropriate for permanent telehealth eligibility.

In addition, the ability to receive care in the home decreases visits to unfamiliar places that may cause agitation in people with dementia and can ease some burden on caregivers. This increased flexibility can reduce interruptions in access to this kind of quality care. We also support and thank the Committee for its leadership in procuring CMS' permanent expansion of licensed practitioners, such as nurse practitioners and physician assistants, who can order Medicaid home health services. Twenty-seven percent of older individuals with Alzheimer's or other dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia. We also encourage CMS to support innovative efforts to increase access to telehealth and telemedicine for Medicare beneficiaries for whom access to broadband or technology is problematic.

Addressing Down syndrome and Alzheimer's Disease

The Committee should continue to keep in mind the intersection of Alzheimer's in people living with Down syndrome when considering disaster preparedness policies for both older Americans as well as individuals with disabilities. Studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of beta-amyloid plaques and tau tangles, abnormal protein deposits considered to be Alzheimer's hallmarks. Despite the presence of these brain changes, not everyone with Down syndrome develops Alzheimer's symptoms. According to the National Down Syndrome Society, about 30 percent of people with Down syndrome who are in their 50s have Alzheimer's dementia, and about 50 percent of people with Down syndrome in their 60s have Alzheimer's dementia. Most adults with Down syndrome will not self-report concerns about memory. Diagnosing dementia in a person with Down syndrome can be difficult because of the challenges involved in assessing thinking-skill changes in those with intellectual disabilities. By age 35, each individual's medical record should ideally include detailed information on baseline adult abilities and intellectual, behavioral, and social functions. There should be ongoing evaluations of these functions, which can better assist caregivers when preparing for emergencies.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of older Americans and families affected by Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to ensure quality care for individuals living with Alzheimer's and other dementia before, during, and after public health emergencies.