

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

### **United States House of Representatives Committee on Energy and Commerce, Health Subcommittee Hearing on "Preparing for and Responding to Future Public Health Security Threats"**

**May 11, 2023**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Committee on Energy and Commerce, Health Subcommittee hearing "Preparing for and Responding to Future Public Health Security Threats." The Association and AIM thank the Subcommittee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. Among other issues, this statement highlights strategies to ensure individuals living with Alzheimer's disease and other dementia are adequately supported before, during, and after public health emergencies.

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 aged 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) in 2023. 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.

While the Subcommittee begins the reauthorization process of the Pandemic All-Hazards Preparedness Act, we encourage you 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.

### **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 these 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 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 would 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.

### **Addressing Health Disparities**

Alzheimer's and other dementia disproportionately affect older Blacks and Hispanics more than older Whites. Blacks/African Americans are about one and a half times more likely to develop Alzheimer's than Whites, and Hispanics/Latinos are one to two times more likely to develop Alzheimer's than Whites. In addition, people living with Alzheimer's and other dementia are at increased risk of contracting illnesses due to their typical age and the likelihood of coexisting conditions. A higher prevalence of Alzheimer's and dementia among Blacks/African Americans and Hispanics/Latinos can also mean a higher likelihood of living in long-term care facilities, resulting in greater exposure to illness. In response, it is crucial that long-term care facilities include data on race and ethnicity in their reporting during public health emergencies, and that the data is made publicly available on a timely basis. This will be especially important in ensuring preparedness and targeted support for future public health emergencies.

The COVID-19 pandemic further exposed health differences that exist between racial and ethnic groups due to economic and social conditions. During public health emergencies, these conditions can isolate people from the resources needed to prepare and keep their families safe. We urge the Subcommittee to consider adding a recommendation to address health disparities when reauthorizing this important legislation.

### **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 the inclusion of provisions to expand 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. Telehealth is critical in helping better manage these chronic conditions, especially for vulnerable populations in uncertain times.

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 people 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.

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 Subcommittee 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.

## **Conclusion**

Again, we thank you for your commitment to reauthorizing this important bipartisan legislation, which will strengthen the public health safety infrastructure for all Americans, including those living with Alzheimer's and other dementia, and their caregivers. We look forward to working with you as the Pandemic All-Hazards Preparedness Act reauthorization effort moves through the legislative process, and again urge you to keep individuals living with dementia in mind as you develop this bill.