

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

United States Senate Special Committee on Aging Hearing on "Preparing for Disasters: Unique Challenges Facing Older Americans"

May 14, 2025

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 "Preparing for Disasters: Unique Challenges Facing Older Americans." 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. 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 separately incorporated advocacy affiliate, working in 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.

Over 7 million Americans aged 65 and older are living with Alzheimer's dementia in 2025. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$384 billion in 2025 (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$246 billion – or 64 percent – while out-of-pocket spending is projected to reach \$97 billion. Total payments for health care, long-term care, and hospice for people living with dementia are projected to rise to nearly \$1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and the health care system. Unfortunately, our work is only growing more urgent.

Improved Response Coordination

People living with Alzheimer's and other dementias are uniquely vulnerable during disasters and public health emergencies. 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 crisis, 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 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. Emergency responders and shelter staff would also greatly benefit from specific training about the signs and symptoms of dementia and other cognitive impairments. To accomplish this, the Alzheimer's Association and the Federal Emergency Management Agency (FEMA) have collaborated on several fronts, including the Association moderating a panel for FEMA during their 2023 Disaster Preparedness and Older Adults Summit: "Coordinating With & Training Law Enforcement & First Responders to Help People With Alzheimer's & Dementia" session. This Summit brought together community-based organizations, federal agencies, and emergency management professionals to discuss disaster preparedness resources, programs, and services

for older adults, as well as the unique challenges, needs, and capabilities of older adults in emergency preparedness to strengthen federal response efforts.

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 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. Overall, 2.7 times more Medicare beneficiaries with Alzheimer's or other dementias have four or more chronic conditions (excluding Alzheimer's disease and other dementias) than Medicare beneficiaries without dementia. Telehealth is critical in helping better manage these 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 allows 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 Congress 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 advancing issues vital to the millions of families affected by Alzheimer's and other dementias. We look forward to working with the Committee in a bipartisan way to address the critical challenges facing the dementia community during public health emergencies.