



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

United States House Committee on Ways and Means, Subcommittee on Health Hearing on "Examining the COVID-19 Nursing Home Crisis"

June 25, 2020

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 Ways and Means, Subcommittee on Health hearing entitled "Examining the COVID-19 Nursing Home Crisis" 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. This statement provides an overview of specific policies that would help people living with Alzheimer's and other dementia during the COVID-19 pandemic.

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. AIM is the Association's sister organization, 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 development of approaches to reduce the risk of developing dementia.

Long-Term Care Recommendations

The COVID-19 pandemic continues to create additional challenges for people living with dementia, their families, and caregivers. These challenges are particularly being felt in long-term care settings. Nursing homes and assisted living communities are on the frontlines of the COVID-19 crisis, where 48 percent of nursing home residents are living with dementia, and 42 percent of residents in residential care facilities have Alzheimer's or other dementia. Residents with dementia are particularly susceptible to COVID-19 due to their typical age, their significantly increased likelihood of coexisting chronic conditions, and the community nature of long-term care settings. Across the country these facilities, their staff, and their residents are experiencing a crisis due to a lack of transparency, an inability to access the necessary testing, inaccurate reporting, and more. According to some estimates, more than 28,000 residents and workers have died from the coronavirus at nursing homes and other long-term care communities.

The Alzheimer's Association recently released new policy recommendations, [*Improving the State and Federal Response to COVID-19 in Long-Term Care Settings*](#), to address the immediate and long-term issues impacting care facilities during the COVID-19 pandemic. These recommendations focus on four main areas: enhancing testing in long-term care community settings; implementing necessary reporting; developing protocols to respond to a rise in cases; and ensuring all facilities have necessary support, like personal protective equipment (PPE). Each nursing home and assisted living community must have the onsite testing capability to verify that all residents, staff, and visitors are free of COVID-19 infection, whether or not they are symptomatic. Government support is needed to ensure accelerated production and delivery of testing, with rapid turnaround testing staffed by trained personnel. Once this testing is

implemented, all cases of COVID-19 at nursing homes and assisted living communities need to be reported immediately and accurately. Additionally, these reports should be updated upon remission, death, transfer, or other appropriate status update. With all appropriate privacy safeguards for individuals, this reported data should be freely and immediately accessible to everyone, down to the facility level. As “hot spots” occur, they must be dealt with urgently and effectively. Any reported cases should trigger careful, ongoing monitoring and, if conditions warrant, “strike teams” should be deployed to the facility to provide needed support until the outbreak is appropriately contained and eliminated. Finally, all nursing homes and assisted living communities must have full access to all needed PPE, testing equipment, training, and external support to keep them COVID-19 free. Importantly, this includes requiring nursing homes and assisted living communities to address social isolation and ensure people with Alzheimer’s and other dementia are able to communicate with designated family and friends. As the Committee and Congress work to craft the next COVID-19 response package, we respectfully request that you include these policy solutions to help protect this vulnerable population.

COVID-19 Impact on Health Disparities

The Alzheimer’s Association is committed to the inclusion of all communities and the advancement of health equity through conversations, work, and partnerships. The COVID-19 pandemic has 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.

Alzheimer’s and other dementia disproportionately affect older blacks/African Americans and Hispanics/Latinos than older whites. Black/African Americans are two to three 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 having serious complications relating to COVID-19 due to their typical age and 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 COVID-19.

Emergency Preparedness in Long-Term and Community-Based Care Settings

One of the most important steps in providing quality dementia care is to know the person, the central tenet of the *Alzheimer’s Association’s Dementia Care Practice Recommendations*.¹ In the event of a major disease outbreak, like COVID-19, or disaster, it may be more difficult for temporary staff members or those working in a new department or other health care setting to know the person. Ensuring staff, including temporary or substitute staff members, in long-term or community-based care settings have access to a personal information form for residents living with Alzheimer’s or other dementia will allow them to quickly identify essential information about the person to help maintain a stable and comforting environment.

Additionally, people living with dementia may need help communicating with their families and loved ones during a crisis like COVID-19. Providers should consider developing a “What You Should Know” fact sheet to explain what families and friends and staff need to know in the event of an emergency. It should include information on how families can receive updates or talk to a care provider about the person living with dementia. Remember that each family is unique, and

¹ Alzheimer’s Association. (2018). *Alzheimer’s Association 2018 Dementia Care Practice Recommendations*.

for some people their closest supporters may not be biological or legal family members, but friends or community members.

Social Isolation and Project VITAL: Virtual Inclusive Technology for ALI

The COVID-19 pandemic continues to create additional challenges for people living with dementia, their families, and caregivers including compounding the negative consequences of social isolation that many older adults already experience. Social isolation is an issue within the aging community as a whole, exacerbated due to the current public health crisis, and felt particularly hard in the Alzheimer's and dementia community.

Project VITAL, a new initiative from the Alzheimer's Association and the Florida Department of Elder Affairs, is designed to address the negative consequences of social isolation, creating a network for connection, engagement, education, and support of individuals with dementia and their families and caregivers to positively impact social isolation, stress, and well-being. Through the use of customized technology and resources, public-private partnerships will facilitate connections between individuals living with dementia in residential communities and their families; provide opportunities for individualized, person-centered engagement; and offer education and support for staff and families through video-based learning platforms. The initiative was launched in April in Florida, and we encourage Congress to include funding to expand access to Project VITAL to create and strengthen personal connections and support for persons living with dementia, families, and direct care staff during this time of physical isolation.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing policies important to the millions of families affected by Alzheimer's and other dementia. Thank you, Chairman Doggett and Ranking Member Nunes, for your continued commitment to supporting individuals facing social isolation. We look forward to working with the Committee and other members of Congress in a bipartisan way to advance this and other policies that would help this vulnerable population during the COVID-19 pandemic.