



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

United States Senate Finance Committee Hearing on "A National Tragedy: COVID-19 in the Nation's Nursing Homes"

March 17, 2021

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Finance Committee hearing entitled "A National Tragedy: COVID-19 in the Nation's Nursing Homes." 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. This statement provides an overview on the long-term care policy recommendations released by the Association and the impact COVID-19 has had on persons living with dementia living in long-term care facilities.

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.

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.

Long-term care, dementia, and COVID-19

An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia in 2021. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$355 billion (not including unpaid caregiving) in 2021. Medicare and Medicaid are expected to cover \$239 billion or 67 percent of the total health care and long-term care payments for people with Alzheimer's or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer's and other dementias are projected to increase to more than \$1.1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system.

At age 80, approximately 75 percent of people with Alzheimer's dementia live in a nursing home compared with only 4 percent of the general population at age 80. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions. It is critical that all residents of nursing homes, including those in skilled nursing facilities and Medicaid nursing facilities, receive consistent, high-quality care, especially as people can live for many years in these settings.

At least 163,000 residents and employees of nursing homes and other long-term care settings have died from COVID-19, representing over 30 percent of the total death toll in the United States. These 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 another 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 communities, their staff, and their residents are experiencing a crisis due to a lack of transparency, an inability to access the necessary testing and personal protective equipment, incomplete reporting, and more.

To best support individuals living with Alzheimer's and dementia during the pandemic, the Alzheimer's Association released a comprehensive set of long-term care policy recommendations for federal and state lawmakers, [Improving the State and Federal Response to COVID-19 in Long-Term Care Settings](#). These recommendations focus on four areas: (1) rapid point-of-care testing, (2) reporting, (3) surge activation, and (4) providing support.

These policies are designed to create a strong and decisive response to the COVID-19 crisis in all long-term care settings and we were heartened to see them in the American Rescue Plan Act of 2021. We thank you for including these important provisions and strongly believe these provisions are critical to our populations and represent a significant step forward in improving their care during this pandemic and beyond.

Long-term care recommendation specifics

We support the inclusion of dedicated funding for testing and tracing in nursing homes and assisted living communities. All cases of COVID-19 in these settings need to be reported immediately and accurately. 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 all down to the facility level. It is crucial that data on race and ethnicity are included in this reporting, which will be especially important in ensuring targeted support for the entirety of the COVID-19 pandemic, and preparedness for potential future pandemics.

As "hot spots" occur, they must be dealt with urgently and effectively. Any reported COVID-19 cases should trigger careful, ongoing monitoring and, if conditions warrant, well-trained and equipped strike teams should be deployed to the facility to provide needed support until the outbreak is contained and eliminated. All nursing homes and assisted living communities must have full access to all needed personal protective equipment, testing equipment, training and external support to keep them COVID-19-free. We also strongly support policies to increase access to televisitiation technologies to address social isolation in long-term care settings, which can have a devastating impact, to ensure people with dementia are able to communicate with designated family and friends.

Furthermore, now that the first safe and effective vaccines are approved, we urge the continued prioritization of access for Americans over the age of 65, particularly those in long-term care settings. This is consistent with the Centers for Disease Control and Prevention's recommendation that long-term care residents be prioritized for access to vaccines, as well as the health care workers caring for some of the most vulnerable in our country and who provide an enormous service to society as a whole.

Finally, we ask that dedicated funding for home- and community-based services continues. People living with dementia make up a large proportion of all elderly people who use these important benefits. In fact, 31 percent of individuals using adult day services have dementia. Access to these services can help people with dementia live in their homes longer and improve quality of life for both themselves and their caregivers. For example, in-home care services, such as personal care services, companion services, or skilled care can allow those living with dementia to stay in familiar environments and be of considerable assistance to caregivers. Adult day services can provide social engagement and assistance with daily activities. Given the demands on and responsibilities of caregivers, respite services are also critical to their health and well-being, and may allow people with dementia to remain in their homes longer.

Nursing Home Legislation

The Alzheimer's Association and AIM have endorsed the Nursing Home Reform Modernization Act which would help ensure high-quality care by establishing an Advisory Council on Skilled Nursing Facility Rankings under Medicare and Nursing Facility Rankings under Medicaid at the Department of Health and Human Services (HHS). This new Advisory Council would provide HHS with recommendations on how to rank high-rated and low-rated facilities, with information on those rankings posted publicly to the Nursing Home Compare website. Importantly, the Special Focus Facility Program would transition to the low-rated facility program and Quality Improvement Organizations would work with those low-rated facilities to improve their quality of care through on-site consultation and educational programming. When choosing a facility for themselves or their loved ones, families deserve to have all the information available in a clear, easily digestible way. We appreciate that this bipartisan bill also directs HHS to utilize focus groups and consumer testing to ensure these ratings are easily understood by older adults, individuals with disabilities, and family caregivers.

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 Wyden and Ranking Member Crapo, for your continued commitment to supporting individuals living in nursing homes including persons living with Alzheimer's disease and other dementia. We look forward to working with the Committee in a bipartisan way to advance policies that would help this vulnerable population during the COVID-19 pandemic and beyond.