



The Honorable Charles Schumer
U.S. Senate Majority Leader
S-221, The Capitol
Washington, DC 20510

The Honorable Mitch McConnell
U.S Senate Minority Leader
S-230, The Capitol
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker of the House
H-232, The Capitol
Washington, DC 20515

The Honorable Kevin McCarthy
House Minority Leader
H-204, The Capitol
Washington, DC 20515

February 23, 2021

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker Pelosi, and Minority Leader McCarthy:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM also thank you for your crucial work to support families and businesses affected by COVID-19. We write again today to ask you to pass policies that are urgently needed now to protect and support the millions of Americans living with Alzheimer's and other dementia, and their caregivers, during this pandemic. Specifically, we urge you to provide funding for policies to assist those living in long-term and community-based care settings.

As reported in the [New York Times](#), new research published in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* examined electronic health record data from 61.9 million American adults and found that risk of contracting COVID-19 was twice as high for people living with dementia than those without it. Furthermore, African Americans with dementia were three times as likely to contract COVID-19 compared to Whites. These preliminary findings suggest a frightening reality of the vulnerabilities associated with living with dementia, and illustrate well-known health disparities that must be addressed.

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 has 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 urge you to prioritize these actions to protect the most vulnerable among us.

Specifically, 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 vaccine is 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. We also note here that the Alzheimer's Association and AIM recently urged the Centers for Disease Control and Prevention and the Centers for Medicare & Medicaid Services to develop and issue guidance on vaccination and safe visitation between residents and families.

Finally, we ask that you also provide dedicated funding for home- and community-based services. 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.

We are particularly heartened to see the long-term care provisions in the American Rescue Plan Act of 2021 which is currently moving through the legislative process in the House of Representatives. We strongly believe these provisions are critical to our populations and represent a significant step forward in improving their care during this pandemic and beyond. We look forward to seeing these policies signed into law and continuing to work with Congressional leaders to advance additional long-term policies as outlined in this letter.

Our nation has not done enough to support Americans living in long-term communities during the COVID-19 pandemic. We urge you to prioritize the above policies that are urgently needed now to help protect our most vulnerable populations. If you have any questions about this or any other legislation, please contact Rachel Conant, Vice President of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Egge', with a stylized flourish at the end.

Robert Egge
Chief Public Policy Officer
Executive Vice President, Government Affairs
Alzheimer's Association