

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

July 31, 2020

## Dear Majority Leader McConnell:

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 appreciate provisions in the Health, Economic Assistance, Liability Protection, and Schools (HEALS) Act focused on providing emergency support and COVID–19 protection for nursing homes. As negotiations on the next COVID-19 response package continue, we urge you to consider additional provisions to meet the unique needs of people living in all long-term care settings, many of whom are living with Alzheimer's and other dementia.

The COVID-19 pandemic continues to create additional challenges for people living with dementia, their families, and caregivers. These challenges are particularly urgent 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 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 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 reports, more than 54,000 residents and employees of nursing homes and long-term care facilities have died, representing more than 40 percent of the total death toll in the United States.

The Alzheimer's Association and AIM thank you for including policies in the HEALS Act that would help protect this vulnerable population in nursing homes, such as establishing COVID-19 strike teams. 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. We also appreciate provisions to increase testing, promote infection control, and increase reporting transparency. These policies are consistent with the Alzheimer's Association's recently-released policy recommendations, *Improving the State and Federal Response to COVID-19 in Long-Term Care Settings*. However, we urge you to consider policies to protect those living in all long-term care settings, including assisted living communities. We also ask that you ensure all long-term care

facilities have rapid point of care COVID-19 testing and necessary equipment, like personal protective equipment (PPE). It is also crucial that data on race and ethnicity is included in reporting on long-term care COVID-19 cases, which will be especially important in ensuring preparedness and targeted support for a potential second wave of COVID-19 or other future pandemic. We also strongly support policies 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.

We hope you will consider including several additional policies as you work to finalize and pass the next COVID-19 response package. The Promoting Alzheimer's Awareness to Prevent Elder Abuse Act (H.R. 6813/S. 3703) would improve interactions between justice personnel and people with Alzheimer's and other dementia. With the current COVID-19 pandemic and given the growing population of persons with dementia, police, emergency personnel, and social workers will increasingly encounter these vulnerable individuals. Working with those with dementia can be fundamentally different from working with other older victims of abuse or exploitation. For example, individuals living with dementia often have difficulty understanding or explaining situations. Common behaviors experienced by individuals living with Alzheimer's and other dementias could be viewed as uncooperative, disruptive, or combative unless professionals have training on their unique needs. This bipartisan bill is consistent with the National Plan to Address Alzheimer's Disease and will help ensure greater success for the Department of Justice's efforts to combat elder abuse, neglect, and financial fraud targeting seniors. This bill would require the Department of Justice to develop training materials to assist professionals supporting victims of abuse living with Alzheimer's and other dementia. Dementiaspecific training materials for these professionals will improve the quality of their interactions with individuals living with Alzheimer's and other dementia, and will also help protect them from elder abuse.

We also ask that you include the bipartisan *Improving HOPE for Alzheimer's Act* (H.R. 1873/S. 880), which would educate clinicians on Alzheimer's and dementia care planning services available through Medicare. As the COVID-19 pandemic continues to challenge health systems worldwide, it raises many important issues including care planning in the presence of acute life-threatening illness, especially for patients with chronic diseases like Alzheimer's and other dementia. Robust care planning is the first step to learning about long-term care options and selecting the preferred, most appropriate services for persons with dementia, families, and caregivers. Analyses show dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. Alzheimer's and related dementia also complicate the management of other chronic conditions, so care planning is key to their management and better care coordination. The availability of CPT® code 99483, care planning for persons with cognitive impairment, is an important step in that direction; however we must ensure that clinicians are aware of this code. Nearly half of Congress has cosponsored this vital legislation.

As you refine the final legislative package, we encourage you to include relief for charitable nonprofits. Nonprofits of all sizes are essential to the well-being of our communities, and communities are relying on nonprofits now more than ever. The Alzheimer's Association has continued our mission during the pandemic, providing care consultations, caregiving tips, and 24/7 access to free, confidential support. But the financial impact of the crisis threatens our ability to continue to serve all those touched by Alzheimer's and dementia--a population that will only grow in the coming years. Large charities like the Alzheimer's Association need access to credit, including loan forgiveness. This is critical, as each dollar spent on loan and interest repayment is a dollar diverted from our constituents. We urge Congress to make the necessary amendments to the Main Street Lending program to allow the Federal Reserve to provide loans and loan guarantees with an option for forgiveness.

Finally, we ask that you include provisions to expand the use of technology-enabled collaborative learning and capacity-building models. These education models, often referred to as Project ECHO, can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with Alzheimer's. During the COVID-19 pandemic, Project ECHO is helping primary care physicians in real-time understand how to use validated assessment tools appropriate for virtual use to make early and accurate diagnoses, educate families about the diagnosis and home management strategies, and help caregivers understand the behavioral changes associated with Alzheimer's, which can be heightened during isolation. Project ECHO is also helping long-term care providers understand in real-time how to train temporary staff that may not be familiar with how to best care for people with Alzheimer's, implement important health strategies such as hand-washing and social distancing for people with Alzheimer's, and effectively communicate with residents to help them understand the COVID-19 pandemic. In fact, the Alzheimer's Association developed a special topic Project ECHO dementia series to help assisted living communities during COVID-19 based on our guidelines, Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting.

Again, the Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia. 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,

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Alzheimer's Association