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

United States Senate Special Committee on Aging
Hearing on "Caring for Seniors Amid the COVID-19 Crisis"

May 21, 2020

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's hearing entitled "Caring for Seniors Amid the COVID-19 Crisis." 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 of specific policies that would help people living with Alzheimer's and other dementia during the COVID-19 pandemic, including long-term care policy recommendations, the *Promoting Alzheimer's Awareness to Prevent Elder Abuse Act* (S. 3703/H.R. 6813), the *Improving HOPE for Alzheimer's Act* (S. 880/H.R. 1873), and efforts to expand capacity for health outcomes through Project ECHO.

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 Policy 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.

Promoting Alzheimer's Awareness to Prevent Elder Abuse Act
There are also several bipartisan bills that we hope the Committee and Congress will consider for inclusion in the next response package. We thank Chairman Collins for introducing the *Promoting Alzheimer's Awareness to Prevent Elder Abuse Act* (S. 3703/H.R. 6813), which 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, and working with them 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 dementia could be viewed as uncooperative, disruptive, or combative unless professionals have training on the unique needs of someone living with dementia. 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. Dementia-specific 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.

Improving HOPE for Alzheimer's Act
We also ask the Committee and Congress to include the bipartisan *Improving HOPE for Alzheimer's Act* (S. 880/H.R. 1873), 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.

Expanding Capacity for Health Outcomes (Project ECHO)
Finally, we ask that you consider crucial 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 in real-time understand 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.

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. We also thank Ranking Member Casey for introducing the *Nursing Home COVID-19 Protection and Prevention Act*, which would provide $20 billion to help states, nursing homes, and intermediate care facilities contain the spread of COVID-19. 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, including long-term care policy recommendations, the *Promoting Alzheimer's Awareness to Prevent Elder Abuse Act* (S. 3703/H.R. 6813), the *Improving HOPE for Alzheimer's Act* (S. 880/H.R. 1873), and efforts to expand capacity for health outcomes through Project ECHO.