



The Honorable Nancy Pelosi  
Speaker  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Kevin McCarthy  
Minority Leader  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Chuck Schumer  
Majority Leader  
U.S. Senate  
Washington, D.C. 20510

The Honorable Mitch McConnell  
Minority Leader  
U.S. Senate  
Washington, D.C. 20510

September 13, 2021

Dear Speaker Pelosi, Minority Leader McCarthy, Majority Leader Schumer, and Minority 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 bipartisan leadership on issues important to Americans living with Alzheimer's and other dementias, and their caregivers. We write today to ask you to pass policies that are urgently needed to support these individuals. We respectfully request that you include important provisions in the forthcoming budget reconciliation package including additional funding for home- and community-based services (HCBS) and make permanent both the Money Follows the Person program and the spousal impoverishment protections.

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 these individuals 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. Unfortunately, our work is only growing more urgent.

### **Home- and Community-Based Services: Needs of the Alzheimer's and Dementia Community**

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community, and states are driving much of the development of and better access to HCBS. State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

Several states are implementing innovative solutions to address Alzheimer's in the Medicaid and non-Medicaid spaces by developing critical, cost-effective, dementia-specific HCBS programs.

These programs are allowing people with dementia and their caregivers to access services and supports that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and to enjoy a greater quality of life. Medicaid should adopt a core set of home- and community-based services that are specifically designed for people with dementia. A core set of HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible

People living with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and nursing home care. Additionally, 32 percent of individuals using home health services have Alzheimer's or other dementias. Persons affected by dementia use a wide range of long-term supports and services, for example:

*Adult day services.* Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias. Ten percent of adult day services specialize in caring for individuals with Alzheimer's disease or other dementias. The median cost of adult day services is \$74 per day, and the cost of adult day services has increased 1.5 percent annually over the past five years.

*Residential care facilities.* Forty-two percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias. Fifty-eight percent of residential care facilities offer programs for residents with dementia. The median cost for care in an assisted living facility is \$4,300 per month, or \$51,600 per year, and the cost of assisted living has increased 3.6 percent annually over the past five years.

*Nursing home care.* Forty-eight percent of nursing home residents have Alzheimer's or other dementias. Nursing home admission by age 80 is expected for 75 percent of people with dementia compared with only four percent of the general population. 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. The average cost for a private room in a nursing home is \$290 per day (\$105,850 per year) and the average cost of a semi-private room is \$255 per day (\$93,075 per year). The cost of nursing home care has increased three percent annually over the past five years for both private and semi-private rooms.

*Respite.* Given the demands on and responsibilities of caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. Use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. This is consistent with the growing demand the Alzheimer's Association hears from our constituents. Yet availability of respite programs in the community is limited. We applaud Congress's passage of the *Lifespan Respite Care Reauthorization Act* (S. 995/H.R. 2035) to meet this demand.

### **Home- and Community-Based Services: the Impact on Family Caregivers**

While 83 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. Alzheimer's takes a

devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2020, more than 11 million unpaid caregivers provided an estimated 15.3 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of over \$257 billion. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. Nearly one-fourth of Alzheimer's and dementia caregivers are “sandwich generation” caregivers — caring for both someone with the disease and a child or grandchild.

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers much needed support. These services empower caregivers to provide quality care for their loved ones while giving them an opportunity to manage and improve their own health.

Important provisions within the Better Care Better Jobs Act would add much needed funds to home- and community-based services, permanently authorize protections against spousal impoverishment, and make permanent the Money Follows the Person program. Medicaid pays for long-term care services and nursing homes for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias. These important programs will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid.

Again, thank you for your leadership on issues important to Americans living with Alzheimer's and other dementias, and their caregivers. We look forward to working with you on these important provisions in the budget reconciliation process. If you have any questions, please contact Rachel Conant, Vice President, Federal Affairs, at [rconant@alz-aim.org](mailto:rconant@alz-aim.org) or at 202.638.7121.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Egge', with a long horizontal flourish extending to the right.

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