



THE BRAINS BEHIND SAVING YOURS.™

September 17th, 2019

House Committee on Commerce and Labor
Senate Committee on Commerce and Labor
Work Groups on Paid and Family Leave

Dear Chairman Kilgore and Chairman Sturtevant,

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease 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. The Association is the leading voice for Alzheimer's disease advocacy, successfully fighting for critical Alzheimer's research, care and support initiatives at the state and federal level.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2018, more than 16 million family members and friends provided 18.5 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of over \$234 billion¹. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and 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.

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 difficulties¹.

Caring for an individual with Alzheimer's has a negative effect on employment, income and financial security. Among Alzheimer's and dementia caregivers who are employed full or part time, 57 percent said they had to go in late, leave early or take time off because of their caregiving responsibilities. In addition, 18 percent had to go from working full time to part time; 16 percent had to take a leave of absence; and 8 percent turned down a promotion due to the burden of caregiving. More than 1 in 6 Alzheimer's and dementia caregivers had to quit work entirely either to become a caregiver in the first place or because their caregiving duties became too burdensome. Among female caregivers, 17 percent believe they have been penalized at work because of the need to care for someone with Alzheimer's².

The issues surrounding caregiving for an individual with Alzheimer's are complex, but our workforce policies should ensure flexibility and proper supports. Concepts like paid family and medical leave should be fully considered as a part of the solution. Therefore, we encourage you to think about the needs of caregivers for individuals with Alzheimer's and support proposals that keep those caregivers in the workforce.

Sincerely,

A handwritten signature in black ink, appearing to read "Carter Harrison", written over a white background.

Carter Harrison
Sr. Director of Government Affairs, Alzheimer's Association

¹ <https://alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>

² <https://alzimpact.org/media/serve/id/5a31f42654048>