

Congress of the United States
House of Representatives
Washington, DC 20515-0535

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October 26, 2021

The Honorable Frank Pallone
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Anna G. Eshoo
Chairwoman
Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member
Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Pallone, Ranking Member Rodgers, Chairwoman Eshoo, and Ranking Member Guthrie:

Thank you for organizing today's hearing, entitled "Caring for America: Legislation to Support Patients, Caregivers, and Providers," in order to consider, inter alia, H.R. 1474, the Alzheimer's Caregiver Support Act. I introduced this important bill along with my Republican colleague, Congressman Christopher H. Smith, to address the devastating impact of Alzheimer's disease on unpaid caregivers.

Alzheimer's is a tragic disease affecting more than five million Americans, and it was the sixth leading cause of death in the United States prior to the COVID-19 pandemic.¹ In 2021, the direct cost of care for Alzheimer's and other dementias was projected to reach \$355 billion, including \$239 billion in Medicare and Medicaid payments. At the current rate, the direct cost of care for these tragic conditions will reach \$1.1 trillion by 2050.²

Caregivers for Alzheimer's patients face a variety of challenges, ranging from assisting patients with feeding, bathing, and dressing to helping them take their medications, managing their finances, and making legal decisions. According to the Centers for Disease Control and Prevention, more than 16 million Americans provide more than 17 billion hours of unpaid care for family and friends living with Alzheimer's and related dementias.³ The Alzheimer's Association

¹ Centers for Disease Control and Prevention, "Deaths from Alzheimer's Disease – United States, 1999-2014" (https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm?s_cid=mm6620a1_w).

² Alzheimer's Association, "Facts and Figures" (<https://www.alz.org/alzheimers-dementia/facts-figures>). See "Costs."

³ Centers for Disease Control and Prevention, "Caring for a Person with Alzheimer's Disease or a Related Dementia" (<https://www.cdc.gov/aging/caregiving/alzheimer.htm>).

estimated that the value of care provided by unpaid caregivers is nearly \$257 billion per year.⁴ Furthermore, when compared with caregivers for people without dementia, twice as many caregivers for people with dementia indicate substantial emotional, financial, and physical difficulties.⁵

The impact of Alzheimer's on caregivers among racial and ethnic minorities and low-income communities is often especially severe. African Americans, Latinos, other minorities, and low-income families are less likely to have access to the training and support services that could assist them with the multitude of challenges that caregivers inevitably encounter when caring for a loved one with Alzheimer's.

I introduced the Alzheimer's Caregiver Support Act to help families face these daunting challenges. My bill authorizes grants to public and non-profit organizations to expand training and support services for families and unpaid caregivers of patients with Alzheimer's disease or a related dementia. The bill requires the Secretary of Health and Human Services to coordinate with the Office of Minority Health and the Office of Women's Health in order to ensure that women, minorities, and medically underserved communities will benefit from the program.

Expanding access to training and support services will improve the ability of caregivers to provide effective and compassionate care, will promote the physical and mental health of caregivers, and could lower overall care costs by allowing those living with dementia to remain in their homes with their loved ones while delaying placement in more costly institutional settings.

The Alzheimer's Caregiver Support Act now has 156 bipartisan cosponsors, and it has been endorsed by the Alzheimer's Association, the Alzheimer's Foundation of America, the Alzheimer's Impact Movement, and Alzheimer's Los Angeles. Copies of their endorsement letters are attached. Companion legislation introduced in the United States Senate (S. 56) by Senators Amy Klobuchar and Susan Collins has 10 bipartisan cosponsors.

I sincerely and wholeheartedly appreciate your attention to the needs of patients, caregivers, and families affected by Alzheimer's, and I look forward to your favorable consideration of the Alzheimer's Caregiver Support Act.

Sincerely,

A handwritten signature in cursive script that reads "Maxine Waters".

Maxine Waters
Member of Congress

Enclosures (3)

⁴ Alzheimer's Association, "Facts and Figures" (<https://www.alz.org/alzheimers-dementia/facts-figures>). See "Quick Facts."

⁵ Alzheimer's Association, "Facts and Figures" (<https://www.alz.org/alzheimers-dementia/facts-figures>). See "Caregivers."



The Honorable Maxine Waters
U.S. House of Representatives
Washington, DC 20515

The Honorable Chris Smith
U.S. House of Representatives
Washington, DC 20515

March 3, 2021

Dear Representatives Waters and Smith:

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 their caregivers. The Alzheimer's Association and AIM strongly supports the bipartisan Alzheimer's Caregiver Support Act which would provide much needed relief for our nation's caregivers.

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% 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 people with Alzheimer's and other dementias 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.

The burden of caring for individuals with Alzheimer's and other dementias extends to millions of Americans caring for those with the disease. In 2020, more than 11 million unpaid caregivers provided 15.3 billion hours of care valued at nearly \$257 billion. Alzheimer's caregivers also report higher levels of stress, depression and worse health outcomes when compared to others who are providing care to individuals without dementia. The physical and emotional impact of dementia caregiving is estimated to have resulted in \$11.8 billion in health care costs in the United States in 2018. The unique challenges and needs of dementia caregiving and the impact of dementia requires comprehensive and robust action for this large and growing number of caregivers. The more caregivers understand Alzheimer's disease or other dementia, the better they can care for their loved ones and themselves.

The Alzheimer's Caregiver Support Act would give these caregivers and their families much needed support by providing grants to public and non-profit organizations to expand and improve training and support services. These services empower caregivers to provide quality care for their loved ones while giving them tools to manage and improve their own health. The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementias. We look forward to working with you to advance this bill. If you have any questions about this or any other legislation, please contact Rachel Conant, Senior Director of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

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



ALZHEIMER'S FOUNDATION OF AMERICA

February 8, 2021

The Honorable Maxine Waters
United States House of Representatives
2221 Rayburn House Office Building
Washington, DC 20515

Dear Rep. Waters:

On behalf of the Alzheimer's Foundation of America (AFA), a national nonprofit that unites more than 2,200 member organizations in the goal of providing support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide, I am writing to support your introduction of the *Alzheimer's Caregiver Support Act*.

AFA has long supported measures that will enhance caregiver training for those who serve persons with dementia. Such training provides better outcomes for both the person living with dementia and their care partners; as well as having the potential to lower care costs by delaying placement in more costly institutional settings.

By making grants to health care providers to expand training and support services for families and caregivers of individuals living with Alzheimer's disease, the *Alzheimer's Caregiver Support Act* will empower family caregivers by giving them the tools to allow their loved one to live independent for as long as possible.

We appreciate you leading the effort to further enhance the training and support of family caregivers which will better their lives and the lives of their loved ones living with dementia. Please let me know if AFA can ever be of help as you work with your colleagues in Congress to pass this important and vital legislation. If you have any further questions, please feel free to contact me at 866-232-8484, or Eric Sokol, AFA's vice president of public policy, at 202- 643-9601.

Sincerely,

A handwritten signature in black ink, appearing to read 'C.J. Fuschillo, Jr.', written in a cursive style.

Charles J. Fuschillo, Jr.
President and CEO



**Alzheimer's
LOS ANGELES**

844.HELP.ALZ
AlzheimersLA.org

4221 Wilshire Blvd, Ste 400, Los Angeles, CA 90010

June 18, 2021

Representative Maxine Waters
U.S. House of Representatives
2221 Rayburn House Office Building
Washington, D.C. 20515

RE: Support for the Alzheimer's Caregiver Support Act (H.R. 1474)

Dear Representative Waters,

Alzheimer's Los Angeles strongly supports the Alzheimer's Caregiver Support Act. As a local non-profit organization, serving the greater Los Angeles region for over 40 years, we know firsthand the significant impact this legislation will have on the families that we serve.

The estimated 11 million unpaid caregivers are the backbone of the Alzheimer's and dementia industry. These people are spouses, sons, daughters, neighbors, friends. They are disproportionately women and people of color. They provide help with a variety of activities of daily living like preparing meals, providing transportation, and managing finances. They also provide higher levels of care like bathing, feeding, toileting, and managing behavioral issues like aggression and wandering.

Many caregivers are doing all of this without any training or support. Because there is no known cure and Alzheimer's is a progressive disease, caregivers can experience increasing levels of stress, depression, new and worsening health problems and financial burden as the disease progresses. During the COVID-19 pandemic, we saw the isolation, stress, and challenges of caregiving exacerbated. With outbreaks of coronavirus in nursing homes and people with dementia being at increased risk for infection, and the shutdown of in person supports like adult daycare programs, Alzheimer's caregivers were even more challenged.

The Alzheimer's Caregiver Support Act will provide grants for organizations and agencies to provide Alzheimer's caregiver education and training to unpaid family caregivers. As an organization that provides caregiving education to families, we know how important it is for caregivers to have access to this information. Alzheimer's Los Angeles provides the evidence-based caregiver education program, *Savvy Caregiver*, which teaches family members basic knowledge, skills and attitudes to be effective caregivers. Our program has also been culturally adapted and translated into Spanish to deliver to the Latino community. Among other outcomes, the program has been proven to reduce caregiver depression and anxiety while it improves tolerance for

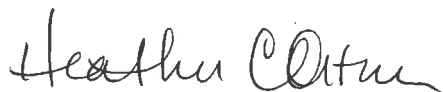


challenging behaviors. With your legislation, more families can have access to education programs such as ours and caregivers can continue to provide care with confidence.

The prioritization of medically underserved populations is a critical piece to the Alzheimer's Caregiver Support Act. Alzheimer's disproportionately impacts communities of color. African Americans are twice as likely to get Alzheimer's than Whites, and Latinos are 1.5 times as likely than Whites. And Latino, Black, and Asian American caregivers have higher care demands, are less likely to use outside help, and suffer greater depression when compared to Whites.

Caregiving is tough, but with education and support, it can help those along their caregiving journey. We applaud your continued commitment to our Alzheimer's families, and we thank you for introducing the Alzheimer's Caregiver Support Act. We look forward to supporting you as you advance this bill. As a local organization, please feel free to use us as a resource for you and your constituents. If you have any questions, please contact Barbra McLendon, Public Policy Director, at bmclendon@alzla.org or 323-930-6290.

Sincerely,

A handwritten signature in black ink that reads "Heather Cooper Ortner". The signature is written in a cursive, flowing style.

Heather Cooper Ortner
President & CEO
Alzheimer's Los Angeles