

Paid Leave Alliance for Dementia Caregivers

Convened by **UsAgainstAlzheimer's**

Paid Leave Alliance for Dementia Caregivers Topline Talking Points

- **The caregiving crisis triggered by the COVID-19 coronavirus spotlights the need for comprehensive paid family leave policies to support vulnerable families caring for a loved one with Alzheimer's or another chronic disease.**
 - Our nation's 5.8 million Americans living with Alzheimer's or a related dementia are cared for by more than 16 million family caregivers.
 - These caregivers provide an estimated 18.4 billion hours of unpaid care with a total value of \$244 billion.
 - Comprehensive paid family and medical leave is critically important for these families and vital for addressing the growing national challenge of dementia care.
- **A comprehensive policy that recognizes care across the lifespan is good for society, good for the economy and good for families caring for loved ones with chronic conditions such as Alzheimer's.**
 - Research by UsAgainstAlzheimer's (UsA2) on employed dementia caregivers finds that nearly 60% reported that using paid leave benefits improved their health and emotional well-being as they provided care.
 - More than 3 in 5 caregivers said paid family and medical leave enabled them to attend doctors' appointments and provide care for their loved ones.
 - More than half of caregivers (55%) who utilized paid family and medical leave benefits said it resulted in better emotional well-being.
 - The need for a strong national policy is clear, as a recent poll of UsA2's online Alzheimer's community found that nearly two-thirds of dementia caregivers think Congress should make paid family and medical leave a priority.
- **The COVID-19 crisis is the latest example of how caregivers of older family members with serious medical conditions are ignored in paid leave protections. Congress must guarantee comprehensive paid family and medical leave that applies to family caregivers during this emergency.**
 - Paid leave policies have focused heavily on parental leave and childcare, largely leaving out caregivers for older individuals living with chronic conditions.
 - Caregivers for individuals 50 and older living with chronic conditions such as Alzheimer's were mostly excluded in the federal response to the COVID-19 coronavirus – the Families First and CARES Acts.
 - When Congress earlier expanded paid leave for federal employees, the change only covered federal employees with young children. Caregivers of adults with chronic conditions were left out.
 - Including paid leave for family caregivers in federal coronavirus response legislation would provide needed support during this national emergency and lay the groundwork for a permanent solution.
 - 74% of dementia caregivers say they are more concerned about their financial health and their family's finances than before the coronavirus.

Paid Leave Alliance for Dementia Caregivers

Convened by **UsAgainstAlzheimer's**

- **A comprehensive and permanent paid leave policy can help alleviate the hardship of dementia care on working family caregivers. Leaving this community behind has severe impacts on the financial and emotional well-being of millions of families.**
 - UsA2's research of employed dementia caregivers found that less than half (49%) reported having access to paid leave benefits. About half (54%) of them used that benefit to care for a loved one.
 - Only one in three employed caregivers report having paid and flexible medical and family leave options to help them balance work and family responsibilities.
 - This lack of paid leave and flexible work options means that caregivers often struggle to be in two places at once: at home providing daily care to their loved ones and at work supporting their employers and co-workers.
 - Six in 10 dementia caregivers report working while providing care. Many find it necessary to pay others to care for their family members, causing significant financial strain.
 - 60% of all employed dementia caregivers experienced financial pressures caused by not being able to work or needing to reduce their number of work hours during their loved one's illness.
 - More than a quarter (27%) of employed caregivers reported going into debt caring for their loved one.
- **The Paid Leave Alliance for Dementia Caregivers is fighting for comprehensive paid family and medical leave for family members caring for adult/older loved ones living with chronic or serious medical conditions.**
 - The Alliance members represent and serve people with dementia and their family caregivers. We have joined together to present a unified voice for dementia family caregivers in the paid leave policy debate. We will work collaboratively to ensure this growing community has the support they need to balance care, treatment, and work.
 - The Alliance's four core principles are that government paid leave policies must 1) include caregivers for loved ones with serious chronic health conditions, 2) provide relief for at-home caregivers, 3) contain meaningful income replacement benefits, and 4) include workplace policies that allows caregivers the flexibility to accompany their loved one to a medical visit.
- **Alzheimer's and related dementias disproportionately affect people of color and women – and their family caregivers – making it an urgent health equity and social justice issue.**
 - Two-thirds of Americans living with Alzheimer's are women, and 60 percent of those caring for someone with the disease are women.
 - In just 10 years, (2030) nearly 40 percent of Americans living with Alzheimer's will be Latino or African American.
 - Because there is no effective treatment or cure for Alzheimer's, caregiving responsibilities can stretch over long periods of time and increase the emotional and financial toll on these families.

Paid Leave Alliance for Dementia Caregivers

Convened by **UsAgainstAlzheimer's**

Supplemental Talking Points on Alzheimer's and African Americans

- African Americans make up just 13.4% of the U.S. population, yet bear 33% of the societal cost of Alzheimer's.
- 46% of African American dementia caregivers reported financial pressures caused by not being able to work due to caregiving.
- Approximately one in four Latino and African American caregivers report that their employers are not supportive in providing them the time off they need to care for their loved ones.

Supplemental Talking Points on Alzheimer's and Latinos

- Currently there are approximately 2 million Latino family caregivers providing unpaid care for individuals living with Alzheimer's or another form of dementia, most without any formal training and while juggling family duties and work responsibilities.
- Alzheimer's will cost the Latino community a total of \$2.3 trillion by 2060.
- 64% of Latino dementia caregivers reported financial pressures caused by not being able to work due to caregiving.
- Approximately one in four Latino and African American caregivers report that their employers are not supportive in providing them the time off they need to care for their loved ones.

Supplemental Talking Points on Intergenerational Impact

- **As the dementia challenge grows, more and more young people are being enlisted into the dementia care community, resulting in emotional and financial disruptions that limit economic opportunity. Paid leave could be a lifeline for young caregivers as they struggle to navigate care and work at this critical time in their lives.**
 - There are 10 million millennials providing care in the U.S. and about one in six are providing care for a loved one living with dementia.
 - Roughly 42% of millennial dementia caregivers are the sole caregivers of their loved one.
 - The overwhelming majority (79%) reported that accessing affordable outside help was very difficult.
 - Nearly 80% experience emotional distress due to caregiving.
 - These caregiving responsibilities result in economic hardship for many millennials, particularly caregivers of color and those with lower levels of education.
 - 33% reported work disruptions due to their caregiving.
 - Four in ten employed millennial caregivers (40%), reported either themselves or someone in their household has had to borrow money or go into debt caring for their loved one.
 - 14% stopped working entirely because of their caregiving duties.
 - Millennial caregivers without a college degree are the least likely to have access to paid family leave and are more likely to give up work to provide care.