## The Connection Between Paid Leave and Dementia Care

It is critical for dementia-serving organizations to engage more in the paid leave dialogue to help alleviate the hardship and stress experienced by millions of unpaid family caregivers through paid family and medical leave policies.

In fact, research by UsAgainstAlzheimer’s (UsA2) on employed dementia caregivers finds that nearly 60% report that the utilization of paid leave benefits improved their health and emotional well-being as they provided care. However, less than half reported having access to these benefits. And, only one in three employed caregivers report having paid and flexible medical and family leave options to help them balance work and family responsibilities.

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. In fact, 60% of dementia caregivers report working while providing care. As a result, many employed caregivers find it necessary to pay others to care for their family members, causing significant financial strain.

### The Link Between Paid Family and Medical Leave and Dementia Care

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<th>Positive Impact</th>
<th>Barriers to Access and Utilization</th>
<th>Economic Impact</th>
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<td>More than 3 in 5 caregivers reported that paid family and medical leave enabled them to attend doctors’ appointments and provide care for their loved ones.</td>
<td>While 49% of employed adult caregivers report having access to paid medical and family leave, just over half (54%) reported using it to care for loved one.</td>
<td>60% of all respondents reported experiencing financial pressures caused by not being able to work, or having to reduce the number of hours they could work during their loved one’s illness.</td>
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<td>More than half of caregivers (55%) who utilized paid family and medical leave benefits reported it resulted in better emotional well-being, compared to 23% of caregivers who didn’t have access to these benefits.</td>
<td>Latino caregivers (60%) and millennial caregivers (64%) were the most likely to use unpaid leave to provide care for a loved one.</td>
<td>Just over a quarter of employed caregivers (27%), and 40% of employed millennial caregivers, reported going into debt caring for their loved one.</td>
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<td>African American caregivers were the most likely to report experiencing barriers to utilizing paid family and medical leave to provide care (36%), followed by Latinos (30%) and millennials (30%).</td>
<td>In light of COVID-19, 74% of dementia caregivers report they are more concerned about their financial health and their family’s finances than before the coronavirus.</td>
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The caregiving crisis triggered by COVID-19 underscores the urgent need for comprehensive paid family leave policies to support vulnerable families during times of crisis and beyond.

However, the paid leave policy conversation during the federal response to the coronavirus has focused heavily on parental leave and childcare. Caregivers for older individuals living with chronic conditions such as Alzheimer’s have been largely left out of the Families First and CARES Acts, adding to an unfortunate policy pattern that must be stopped. Caregivers of adults with chronic conditions were also excluded in earlier legislation passed providing paid leave only for federal employees with young children. 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.

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“Until there is paid leave, it is impossible to find a balance. The 24 hours of stress over 10 years caring for my dad reduced my ability at work…”

Dementia Caregiver
UsAgainstAlzheimer’s A List

Alliance Overview

To advocate for access to paid family leave for family caregivers of individuals living with chronic medical conditions such as Alzheimer’s and related dementias, the Paid Leave Alliance for Dementia Caregivers will focus on four goals:

- Mobilize dementia-serving organizations and those that serve family caregivers to advocate for these individuals in the paid family and medical leave policymaking process.
- Advance the passage of federal paid family and medical leave policies that includes family care for individuals with serious medical conditions.
- Ensure family care is seen as a critical component of a national paid family and medical leave policy.
- Position paid family and medical leave as vital for addressing the growing challenge of dementia care.

The Alliance’s collective work will focus on educating policymakers and their constituents about the positive impact of paid family and medical leave on the dementia and family caregiver communities.
About the Alliance
The Paid Leave Alliance for Dementia Caregivers, convened by UsAgainstAlzheimer’s, is comprised of diverse patient and caregiver advocacy organizations working at the intersections of dementia care, healthy aging, and health equity. The Alliance advocates for access to paid family leave for family caregivers of individuals living with chronic medical conditions such as Alzheimer’s and related dementias. To learn more about the Alliance, its principles, and research, please visit https://www.usaginstalzheimers.org/alzheimers-and-paid-leave.