

A New Frontier in Paid Leave: Supporting Family Caregivers Providing Alzheimer's and Dementia Care

RESULTS FROM A NATIONAL SURVEY OF EMPLOYED ADULT CAREGIVERS
COMMISSIONED BY USAGAINSTALZHEIMER'S



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ALZHEIMER'S DISEASE AND OTHER TYPES OF DEMENTIA HAVE A DEVASTATING SOCIAL AND ECONOMIC IMPACT ON INDIVIDUALS, THEIR CAREGIVERS, AND THEIR COMMUNITIES.

More than 5.7 million Americans currently have Alzheimer's disease, a number that is projected to triple to 16 million by 2050.¹ Someone in the U.S. develops Alzheimer's every 65 seconds², overwhelming not only the afflicted individual, but their entire family. In 2017 alone, 16.1 million family caregivers in the U.S. provided an estimated 18.4 billion hours of unpaid care for people with Alzheimer's and other dementias.³

The struggle to provide daily care to loved ones is particularly challenging for the 60% of dementia caregivers who are also working outside the home.⁴ A recent study found that fewer than 1 in 3 employed caregivers report having paid and flexible medical and family leave options to help them balance work and family responsibilities. These challenges are especially acute in communities of color, where African-American workers are less likely to have access to flexible days and flexible work hours (5.3% and 7.2%, respectively), and Latino workers are significantly less likely to have access to paid sick days or paid vacation (11.5% and 12.4% respectively).⁵ Young people are also

SURVEY FINDINGS AT-A-GLANCE

UsAgainstAlzheimer's June 2018 national online survey of employed adult caregivers for those with Alzheimer's or related dementias found that:

- ▶ Access to paid medical and family leave has a significant positive impact for employed adult caregivers of loved ones with Alzheimer's disease or other types of dementia
- ▶ Despite its benefits, less than half of employed adult caregivers report having access to paid medical and family leave
- ▶ Only slightly more than half of the employed adult caregivers with access to paid medical and family leave reported using it
- ▶ Six in ten caregivers (60%) reported experiencing problems related to 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
- ▶ Just over a quarter of employed caregivers (27%), and 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
- ▶ Most employed adult caregivers reported they would be likely to use additional employer benefits (including the ability to combine, pool and gift benefits), if they were offered by their employer
- ▶ Although these employed adult caregivers surveyed may be at higher family risk for Alzheimer's disease, they are not talking "regularly" about brain health in their households

increasingly sharing the caregiving burden. Of the 10 million millennial caregivers in the U.S. one in six (15%) provides care for someone living with Alzheimer's or another form of dementia, and they report that flexible benefits to support their caregiving arrangements are not usually offered by their employer.⁶

Despite progress, paid and medical leave options are still unavailable to many employed caregivers. Yet they make a major difference in supporting workers with caregiving responsibilities and in helping American employers maximize their productivity, profitability and workforce retention.⁷

Paid medical and family leave has a significant positive impact on caregivers' ability to provide care for their loved ones and on their own health and well-being, but too few employed caregivers either have access to it or are fully utilizing available benefits.

About the Survey

UsAgainstAlzheimer's is fighting to bring a swift end to Alzheimer's and related dementias, while, at the same time, committed to addressing the needs of the enormous existing Alzheimer's population in this country. To better understand the impact of paid medical and family leave on caregiving, UsAgainstAlzheimer's commissioned Public Opinion Strategies, a national research

firm, to conduct a comprehensive national online survey of employed adults caring for a loved one living with Alzheimer's or another form of dementia.⁸ The goal of the survey was to help better understand the role that paid leave plays in supporting caregivers who are providing complex and comprehensive care to family members and to inform more effective solutions to address the family needs of this growing caregiver population.



WHAT IS PAID FAMILY AND MEDICAL LEAVE?

At one point or another, most employees need to take time off work to deal with a serious personal illness or to care for a parent, spouse or child. The Family and Medical Leave Act (FMLA) is a federal law that guarantees unpaid leave to 60% of the current American workforce to tend to their personal and family needs without losing their jobs. An increasing number of companies provide paid medical and family leave benefits which allow employees to continue earning some portion of their pay to address a serious health condition or provide family care.⁹ In addition, some businesses offer other benefits to assist employees with their caregiving responsibilities, such as a more flexible work schedule to extend leave time. There is currently no federal law requiring paid leave, but several states, including California, New Jersey, Rhode Island, New York, Washington and the District of Columbia, have passed new laws that expand paid family leave requirements. At the present time, however, only 15% of U.S. workers have access to paid family leave through their employers.¹⁰

Key Survey Findings

POSITIVE IMPACT OF PAID MEDICAL AND FAMILY LEAVE ON CAREGIVERS AND THEIR LOVED ONES

Access to paid medical and family leave has a significant positive impact for employed adult caregivers of loved ones with Alzheimer's disease or other types of dementia.

Those surveyed who have access to paid medical and family leave report that having access to paid time off to care for their loved ones had a positive impact on their ability not only to provide care but also on their own health and well-being. The specific benefits they reported included their ability to go to their loved one's doctor or treatment appointments and to provide ongoing care. Those respondents with access to paid medical and family leave also pointed out that access to this leave improved their own health and emotional well-being as they provided complex care for family members. In contrast, those employed adult caregivers surveyed without access to paid medical and family leave were more likely to report that their caregiving responsibilities negatively impact their career.

UNEVEN ACCESS TO AND USE OF PAID MEDICAL AND FAMILY LEAVE

Despite its benefits, less than half of employed adult caregivers surveyed reported having access to paid medical and family leave. Slightly less than half (or 49%) of



% POSITIVE IMPACT - HAVE/DON'T HAVE PAID MEDICAL/FAMILY LEAVE	Have Paid Leave (49%)	Don't Have Paid Leave (45%)
Being able to go to your loved one's doctor or treatment appointments	63%	34%
Your ability to provide care for your loved one	62%	34%
Your own emotional well being	55%	23%
Your own health	47%	21%

Survey Question: Did the ability or inability to take paid medical/family leave have a positive impact, a negative impact, or did it not have an impact at all on any of the following for you during the time you cared for your loved one?

those caregivers surveyed reported that they have access to paid medical and family leave, although this varies significantly among those populations surveyed. The sub-groups more likely to report having access to paid medical and family leave include: men (ages 18-49); African Americans (particularly those 18-44); and respondents employed full-time, working in larger companies (501+ employees) and those in middle to higher income households.

Millennials and Latinos with higher levels of education and millennials (ages 18-35), African Americans, and Latinos with salaried jobs were also more likely to have access to paid medical and family leave.

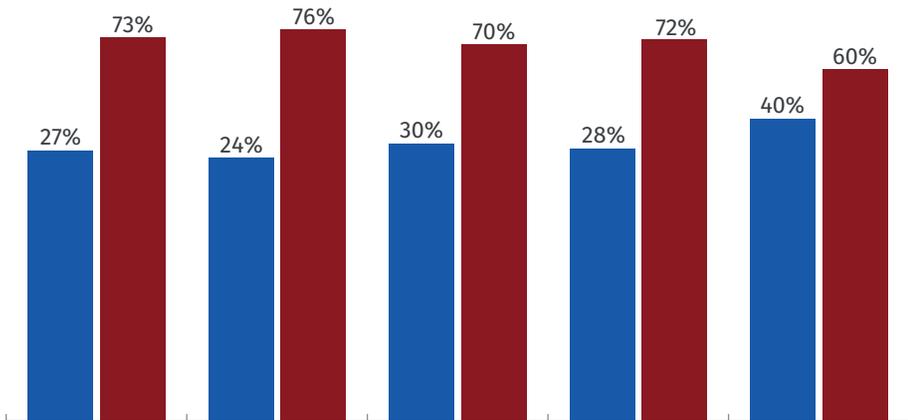
Only slightly more than half of employed adult caregivers who report having access to paid medical and family leave reported using it. The survey found that among the 49% of caregivers with

FINANCIAL CHALLENGES		All Caregivers
A significant problem for you		26%
Only somewhat of a problem for you		34%
Total Problem		60%
Not much of a problem for you		25%
Not a problem at all for you		15%
Total not a Problem		40%

Survey Question: Some caregivers of loved ones with Alzheimer’s or another type of dementia report one challenge they face is the financial pressure caused by not being able to work or having to reduce the amount of hours one can work while caring for their loved one. How about you, was this...?

Caring for a family member with dementia or Alzheimer’s disease changes your life forever. Your priorities are now determined by what is needed by your loved one; your needs and wants are secondary.

– Carmen Pastor, Caregiver for her Mother



■ Yes
■ No

Survey Question: Have you or has anyone in your family had to borrow money or go into debt because of your loved one’s Alzheimer’s or another type of dementia, medical costs, or caregiving costs?

access to paid medical and family leave, only 53% reported actually using it to provide care for their loved ones. Those most likely to utilize available paid medical and family leave included men (ages 18-49) and African Americans (ages 18-44). Caregivers in middle income households (\$60K-\$100K), caregivers living in suburban areas, and those in mid-sized companies (employees 51-500) as were employed millennial caregivers with salaried jobs or with college and post-college educations.

NEGATIVE FINANCIAL IMPACT OF BALANCING WORK AND CAREGIVING RESPONSIBILITIES

Six in ten employed adult caregivers (60%) reported experiencing problems related to 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. 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. As a result, many employed caregivers find it necessary to pay others to care for their family members, causing significant financial strain. Of the survey respondents, 60% reported experiencing some or significant financial challenges.

Just over a quarter of employed adult caregivers (27%) and 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.

When employed adults juggle job and caregiving responsibilities, many find it necessary to borrow money or take on credit card debt in order to employ professional caregivers, so they can go to work. This pressure is particularly intense on employed millennial caregivers (those ages 18-35) who have had fewer years of work experience and tend to have less lifetime savings.

MAXIMIZING AND EXPANDING MEDICAL AND PAID LEAVE BENEFITS

In testing additional employer benefits for employed adult caregivers, most respondents reported either not having or not knowing whether they currently have these additional benefits.

While the survey revealed uneven access to paid medical and family leave by employees, it also found that more than one in ten respondents did not know whether their employers even offered other types of caregiver benefits, such as the option to combine leave benefits, the ability to use flextime or gift unused leave to other employees, or paid eldercare benefits.

But most employed adult caregivers reported they would be likely to use these additional employee benefits if offered by their employer. When the array of potential workplace benefits was defined for respondents, the vast majority reported that they were likely or very likely to take

We all basically went broke. I asked each family member to contribute some money monthly. I even asked her grandchildren to donate a little. Others bought groceries, ran errands and provided respite care by mama-sitting.

- Theresa Vaquez, RN, Caregiver for her Mother

RANKED BY ALL CAREGIVERS % YES	All Caregivers		
	% Yes	% No	% Don't Know
Allows employees to combine other leave benefits such as personal, sick, and vacation time to use for more extended time off with a love one with serious medical condition.	48%	35%	17%
Provides workplace flexibility options for people who need time off on a regular basis to care for their loved one with a serious medical condition. For example, flextime or a flexible work schedule, telecommuting, or overtime hours for later use as time off.	45%	42%	13%
Allows other employees to gift their unused leave to employees who are caring for parents or older relatives or older loved ones that need elder care.	28%	56%	16%
Offers a paid benefit to help employees with the costs of elder care.	18%	64%	18%
Offers a paid benefit to help employees with the cost of child care.	16%	67%	17%

Survey Question: Select whether your employer (offers/offered) each to employees.

advantage of the following options: workplace flexibility options (59% very likely and 86% likely to use benefits if offered by their employer); combining personal, sick and

vacation benefits (56% very likely; 88% likely); eldercare benefits (52% very likely; 84% likely); and allowing co-workers to "gift" their unused time (42% very likely; 73% likely).

PREVENTING ALZHEIMER'S DISEASE AND PREPARING FOR THE FUTURE

Although these employed adult caregivers surveyed may be at higher risk (family history) for Alzheimer's disease, they are not talking "regularly" about brain health in their households. While there is not yet a cure for Alzheimer's, there are interventions to help slow its progress and brain-healthy activities such as regular exercise, a healthy diet and other factors, that can help prevent and slow down the disease. Talking openly about brain health, especially among families who are already caring for a loved one who has Alzheimer's or other types of dementia, plays a key role in prevention and treatment, yet too few discuss it.

Implications for Research and Policy: Recommendations and Next Steps

This public opinion research is an important step in developing new public policy solutions and sources of public and private support for caregivers of loved ones with Alzheimer's and other dementias. Given the unique challenges of employed adult caregivers, particular attention is needed to craft effective approaches to help those struggling to balance their responsibilities at work and at home. The urgency for support

DISCUSSION OF BRAIN HEALTH	All Caregivers	Whites	African Americans	Latinos	Millennials
Regularly discuss it	48%	48%	48%	35%	17%
Occasionally discuss it	45%	45%	45%	42%	13%
Rarely have discussed it	28%	28%	28%	56%	16%
Never have discussed it	18%	18%	18%	64%	18%

Survey Question: Brain health describes normal brain function, including processing and retaining information; performing logical thinking, judgment and perspective; storing and recalling memories; and the ability to concentrate, among other functions of a healthy brain. How often is brain health a topic of conversation in your household?

When I was ready to resume working, job-hunting was difficult. I couldn't help but feel ashamed of the gap on my resume, despite the fact that I was grateful to have spent that time with my dad. No one should have to choose between earning money and caring for a sick loved one.

Caitlin Moran, millennial caregiver



and policy solutions is made clear by the dramatic increase in the projected number of families that will be touched by Alzheimer's over the coming decades (16 million by 2050).

The survey findings make it clear that the availability of and access to paid medical and family leave plays a significant role in providing caregivers with the time and financial support they need to care for their families and to improve their own mental health and well-being. Building on this initial learning, UsAgainstAlzheimer's recommends the following:

1 *Support and promote bipartisan federal and state policy efforts to expand paid medical and family leave:*

The federal Family and Medical Leave Act and a growing number of state laws guarantee continued employment for those who need to take time off to address serious health problems or care for a loved one with Alzheimer's or other types of dementia. Without financial protections, however, many caregivers cannot afford to take advantage of these opportunities. While there is a substantial need for paid medical and family leave, achieving this policy goal without an undue burden on taxpayers, employers and families is a difficult one. Federal and state policy makers should make it a priority to convene health care experts, economists, researchers, community stakeholders, and caregivers to better understand eldercare needs

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UsAgainstAlzheimer's is driven by passion and purpose and is powered by individuals living with dementia and their care partners. We forge innovative and comprehensive solutions to Alzheimer's disease and other forms of dementia. We press for greater urgency and collaboration from government, industry and the scientific community in the quest for an Alzheimer's cure. We act on those beliefs through strategic and disruptive investments in infrastructure, big data, and national and global convening platforms. And we mobilize communities most deeply affected by the disease, including women, African Americans, Latinos, caregivers, veterans, youth, activists, the faith community and researchers.

and to identify equitable policy solutions to address them.

2 *Create a National Employer Task Force on Eldercare to explore innovative caregiver support strategies:*

In light of substantial economic costs of caregiving on American businesses, many employers already offer paid leave, workplace flexibility and other supports to benefit those caring for loved ones with Alzheimer's and other types of dementia. These companies have important knowledge to share about the impact of these benefits on productivity, profitability and workforce retention. The business community should be encouraged to create a national task force that brings together the leaders of large and medium-sized companies and smaller businesses to learn about what works, share funding

strategies, and better identify and meet the needs of both the business community and their employee caregivers.

3 *Study the impact of paid medical and family leave on communities of color, millennials and other sub-populations with less access to benefits:*

All employed caregivers deserve equitable access to paid leave and other eldercare supports. However, this survey and other studies consistently point to a disproportionate economic caregiving impact on and disparate benefits access among caregivers of color, women, low-income communities and millennials. Given the positive impact that access to paid leave has on caregiver stress, emotional well-being and access to higher quality care, more research is needed to determine how disproportionate access to

benefits and supports impacts these populations and to develop strategies that reduce barriers to accessing those supports. Additional research is needed at the national and local levels to understand the disparate effects on these sub-populations and to guide effective, evidence-based policy solutions to help them.

4 *Catalyze a national public education effort, bringing together key stakeholders to educate caregivers and ensure that the availability and scope of benefits for care is understood and utilized:*

As this survey underscores, some employed caregivers may already have access to paid leave, flex time, and other benefits of which they are not even aware. Government, business and community leaders should work collaboratively to educate employees about available benefits and eliminate the barriers that prevent their use.



5 *Make brain health resource materials more widely available to families and caregivers:*

Along with paid medical and family leave and other work-related supports, family caregivers can also benefit from information on the latest Alzheimer's and dementia prevention and treatment options. It is essential that families talk openly about how to work

together to ensure the highest quality care, decrease caregiving stress, and focus on brain health strategies to help prevent similar diseases in the next generation. To encourage these conversations, the government, national advocacy groups, businesses and local stakeholders should increase their efforts to make comprehensive and highly accessible resources available to all communities.

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- 1 Tara Bahrapour [New study ranks Alzheimer's as third leading cause of death, after heart disease and cancer](#). *The Washington Post* (March 2014)
 - 2 Alzheimer's Association. [2017 Alzheimer's Disease Facts and Figures](#).
 - 3 Ibid.
 - 4 National Alliance for Caregiving & AARP, [Caregiving in the U.S.](#) (2015).
 - 5 Center for American Progress, [Who Gets Time Off?: Predicting Access to Paid Leave and Workplace Flexibility](#) (2016).
 - 6 UsAgainstAlzheimer's, [Millennials and Dementia: Caregiving in the United States](#), (2017).
 - 7 Robert Wood Johnson, [Health Policy Brief: Paid Family and Medical Leave](#) (2016)
 - 8 Between June 6-20, 2018, Public Opinion Strategies (POS) conducted a national internet survey of 612 employed adults (with a confidence interval of $\pm 4.5\%$) who care for or have recently cared for a loved one with Alzheimer's disease or another type of dementia. In order to have a large enough sample size to determine attitudes among key audiences, POS conducted oversample interviews to reach a total of N=127 African-American caregivers, N=127 Hispanic/Latino caregivers and N=178 millennial caregivers (ages 18-35).
 - 9 Ibid.
 - 10 Ibid.

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