

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST is an online community of more than 7,500 people living with Alzheimer's or other dementias, and current and former caregivers who are bringing research closer to the lived experience of this disease.



The Pulse of the Community

What Matters Most:

Paid Leave is a Priority for Caregivers

A new UsAgainstAlzheimer's A-LIST® survey shows how important paid family leave is to caregivers for people living with Alzheimer's disease and other dementias, with two-thirds of caregivers saying that Congress should make paid leave a policy priority.

The top findings for the A-LIST survey ([here](#)) document the challenges faced by caregivers and the vital need for a national paid leave policy for those taking care of people with long-term diseases, such as Alzheimer's disease and other dementias.

The survey findings validate [a new 2020 report](#) from the U.S. Centers for Disease Control and Prevention that shows that nearly 1 in 5 family caregivers may be in fair or poor health, going on to describe caregiving as "a public health issue of increasing importance."

This research also builds on a 2018 UsAgainstAlzheimer's [national poll](#) of employed dementia caregivers that found nearly 60% reported that utilization of paid leave benefits improved their own health and emotional well-being as they provided care. However, less than half reported having access. This unpaid work by 40 million Americans, which AARP translates to a value of some \$470 billion a year, affects both health and financial wellness, as well as work.

Nearly 9 in 10

(87%) of those responding to the survey reported they did not receive paid leave while caregiving for a loved one.

Almost half

(48%) of those not receiving paid leave reported the lack of availability as the reason.

Nearly 10%

of respondents changed their employment status to accommodate caregiving.

Nearly a quarter

(23%) felt less focused on their work because of their caregiving responsibilities and nearly 14% reported feeling "nervous all the time," which negatively affects work.

More than 8 in 10

(84%) reported they would be interested in receiving paid leave in the future.

The A-LIST survey results show how valuable the A-LIST surveys and the views are to UsAgainstAlzheimer's and its work.



"I earned a Ph.D only to leave my career to take care of my Mom and then my Dad."

One of our organization's core principles is to amplify the voice of people living with the disease and their caregivers and families in our advocacy work for faster progress on treatments and prevention in the fight to eventually stop Alzheimer's. That includes making sure that elected officials and government agency leaders know the needs, preferences and views of the community when considering laws or policies.

What did we do with these paid leave survey results? First, we publicly shared the findings and reinforced the point that two-thirds of caregivers in the survey want Congress to make paid leave a priority in a blog that was featured by the Diverse Elders Coalition. That blog, which can be read [here](#), was also highlighted by other groups working on paid leave policy, including the [New America Foundation](#) and the [National Partnership for Women and Families](#).

In addition, when the U.S. House Education and Labor Committee held a hearing on paid family and medical leave earlier this month, UsAgainstAlzheimer's submitted comments to the committee that included these A-LIST survey findings on what caregivers say is important to them.

About this Survey

This A-LIST® What Matters Most Insights survey is a quantitative study with 357 respondents, including people who have been diagnosed with dementia, current and past caregivers, those who may be at risk and those who are interested in brain health.

About the A-LIST

The UsAgainstAlzheimer's A-LIST® is a growing online community of more than 7,500 people living with Alzheimer's, other dementias, or mild cognitive impairment, current and former caregivers, people who believe they are at risk, and those interested in brain health. These survey responses are contributing to IRB research that illuminates and validates their lives and experiences. The surveys offer a way to make their views and preferences heard on issues that span the entire scope of living with dementia. The A-LIST® is part of a broader effort by UsAgainstAlzheimer's called AD-PACE, a groundbreaking patient and caregiver-led collaboration of industry, academics, government agencies and advocates.



"I don't think the younger bosses understand the time demands. I wasn't allowed any flexibility. I requested a very short-term solution to address an immediate need and was denied. I never asked for anything again, and didn't tell them when my mother died."

In Their Own Words



“Family leave should be available to all and be paid.”



“I found this nearly impossible. I felt both jobs suffered as a result of caring for my husband. And what is rarely mentioned is the physical/emotional demands placed upon the caregiver. Because of my time demands of caregiving, and my career, there was never any time for myself... and my physical and emotional health declined.”



“I had 10 years fraught with anxiety, not giving either my husband or my job my full attention.”



“Until there is paid leave, it is impossible to find balance. The 24 hours of stress over 10 years caring for my Dad reduced my ability at work, reduced the level of care I could provide him, impacted my physical and mental health and that if my family. It was an impossible situation and through the grace of God we all got through it. Until government steps up and helps find a cure and helps caregivers with tax advantages or paid leave I am afraid that it will still be left in the hands of God. Until lawmakers go through this situation themselves, they will never understand.”



“An employer should offer employees taking care of elder parents the same flexibility as those taking care of children. If not, good employees leave and the cost of replacing and training those people has more negative impacts on the organization.”



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