

# CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 8,600 people living with Alzheimer's and other dementias, current and former caregivers, and those concerned about brain health, who have come together to share and validate the experience of living with this disease and caring for a loved one. We call it the "science of us."



## The Pulse of the Community

### What Matters Most:

The mission of the UsAgainstAlzheimer's A-LIST® is to use survey results to make life better for the broader Alzheimer's and dementia community. UsAgainstAlzheimer's (UsA2) makes sure that policymakers, researchers, health care providers, drug developers, insurers and others who serve this community understand and consider your insights about the Alzheimer's journey when making decisions that affect those living with the disease and caregivers. This Pulse of the Community Issue Brief summarizes four recent A-LIST research projects and the action taken related to each study.

### New Drug Treatments and What Matters Most

The U.S. Federal Drug Administration (FDA) on June 7th approved the drug Aduhelm (also known as "aducanumab"), the first disease-modifying therapy for early-stage Alzheimer's. As part of its approval process for any drug, the FDA is required to consider the value of treatments to patients. In January, we asked A-LIST members what matters most to them when it comes to new Alzheimer's treatments and therapies. We shared the results of this survey with the FDA during its review process for Aduhelm. [Read the summary here.](#)

The survey asked participants what it would mean to them if the FDA approved a drug which allowed them (or a loved one) to maintain a current state of daily functioning for one year, but with the understanding that the disease might continue to progress after a year.



**People living with Mild Cognitive Impairment (MCI) or Mild Alzheimer's disease (AD):**

**63%**

said this would offer some or significant benefit; **10%** said they would not perceive a benefit; and **27%** were unsure.



**Caregivers:**

**76%**

said this would offer some or significant benefit; **6%** said they would not perceive a benefit; **12%** were unsure.

Even if there is a chance of side effects in some people requiring close management by a physician, 78% of people living with MCI or Mild AD considered it important to have access to an FDA-approved treatment that allows them to experience an additional year without worsening symptoms.

Once a drug is deemed sufficiently safe in clinical trials, it can take several years of further study to fully understand how well it works, also known as “efficacy.” In the survey, 84% of respondents with MCI or Mild AD believe that the FDA should factor in the willingness of patients to take the treatment before efficacy is fully studied.

The FDA’s decision to approve Aduhelm also requires the company to conduct a Phase 4 study to assess how the drug works with a wide range of diverse communities.

### Priorities of Caregivers of Color

The A-LIST developed research exploring the concerns and priorities of dementia caregivers of color. Black Americans are twice as likely as non-Hispanic Whites to develop Alzheimer’s; Latinos are 1.5 times as likely. And the needs of dementia caregivers of color are largely ignored or misunderstood by health care providers.

To better understand these needs, we fielded surveys on the burdens experienced by caregivers and caregiver interactions with health care providers. The results of our research were published on June 13 at the 2021 Alzheimer’s Association Addressing Health Disparities Conference in two scientific posters, which can be found [here](#) and [here](#).

#### CAREGIVERS REPORTED TOP BURDENS:

- 63.5% No time for self
- 53.8% Feeling stressed
- 50% Uncertain about the future
- 46.1% Concerns about financial status
- 44.2% Not getting enough sleep
- 42.3% Unable to leave home

The first A-LIST survey asked caregivers about the challenges they face caring for a loved one and the services they use to help ease the burden.

Caregivers reported using educational and referral services, as well as caregiver support groups, but did not use or weren’t aware of other available services, such as respite programs, and home adaptation, transportation and meal delivery services.



#### CAREGIVERS OFFERED ADVICE FOR MANAGING STRESS:

**“My church family helped a lot.”**

**“Leverage technology to stay organized.”**

**“I carve out time on the weekends to work out and partake in activities that I love. I carve out time to spend time with my husband, who also caregives for my mom.”**

In a second A-LIST survey, caregivers were asked about the training and resources they received from their own or their loved ones’ healthcare providers. 68.7% of caregivers reported receiving no training; 14.5% received information about training; 4.8% received training; 12% received training and information.

For those that did receive caregiver training, 50% said it was at the wrong time. And less than half (42.9%) felt the training prepared them for all the situations that they faced.



#### CAREGIVERS WEIGHED IN ON MOST IMPORTANT TRAINING TOPICS:

**“How to be compassionate to individuals with dementia and how not to take their behavior personally.”**

**“Anger Management.”**

**“I wish I had training in basic nursing care.”**

More must be done to connect caregivers of color with existing resources and training with a focus on services relevant to the social determinants of health that create barriers to better care and supports. This could benefit the well-being of caregivers and improve access to higher quality care for those living with dementia.

UsAgainstAlzheimer's is turning this data into action through our [Center for Brain Health Equity](#), a project supported by the U.S. Centers for Disease Control and Prevention, to strengthen our public health response to Alzheimer's and related dementias in communities of color.

The A-LIST study team wishes to thank research partners The Balm In Gilead and the Diverse Elders Coalition. This research was made possible in part by a grant from Genentech.

## Impacts of the Coronavirus Crisis on the Alzheimer's Community

The eighth A-LIST survey on the COVID-19 pandemic was conducted as the United States approached the one-year mark of coronavirus-related restrictions. [The survey](#) showed the coronavirus pandemic and related closures over the past year led to declines in people living with Alzheimer's disease, disrupted daily routines, and caused severe and chronic stress on caregivers left isolated without relief or support. [Read the complete results here.](#)

Nearly three-quarters (72%) of caregivers observed a decline in their loved ones' memory or behaviors, with nearly 31% reporting a significant decline. In addition, nearly half (47%) of the 38 respondents diagnosed with mild cognitive impairment, Alzheimer's or dementia said they believe their cognition has declined.



**"I've had no respite for a year and my anger and stress has skyrocketed." – A-LIST Caregiver**



**"I hope I have a better chance of being able to visit my elderly mum who is withering from loneliness." – A-LIST Caregiver**

## SIGNIFICANT ONGOING STRESS FOR CAREGIVERS



**84% of caregivers** reported having one or more stress symptoms typically found in people experiencing severe stress.

Top-reported caregiver symptoms associated with stress include:

- 44%** Vigilance/being 'super alert'
- 40%** Loss of interest in activities
- 31%** Trouble experiencing positive feelings
- 30%** Sleep problems
- 27%** Difficulty concentrating
- 21%** Irritable/angry behavior

These high levels of severe stress for caregivers have been seen in the A-LIST surveys throughout the past year. This raises serious concerns about the long-term effects and the need for better support systems for caregivers going forward.

According to Dr. Jennifer Olsen, Chief Executive Officer of the Rosalynn Carter Institute for Caregivers, "This research should serve as a call to action that we have a community of caregivers that have been struggling with the combined stress of caregiving and COVID-19, and we cannot develop plans to reopen society without considering caregivers as a population-at-risk. Caregiver health and well-being should not be an afterthought in building the programs and policies needed in a post-pandemic world."

Getting the vaccine offers hope for many of the survey respondents that they will be able to visit loved ones in long-term care communities and reduce fears of transmitting the coronavirus.

## Agitation in Alzheimer's

A common symptom of Alzheimer's is agitation, including emotional distress, excessive movements, or verbal or physical aggression. This can be difficult for those with Alzheimer's and caregivers.

The A-LIST partnered on a study to better understand agitation in Alzheimer's, how caregivers are affected, and the resources available to help. The results were published at the 2020 Clinical Trials on Alzheimer's Disease (CTAD) conference. Read the scientific poster [here](#).

395 caregivers answered the survey, and 75.2% of them cared for a person with Alzheimer's experiencing agitation.

### MOST FREQUENT SYMPTOM REPORTED BY CAREGIVERS:

- 69.4% Resisting care
- 54.9% Pacing, rocking or restlessness
- 45.8% Cursing or shouting

### THE MOST COMMON EFFECTS OF AGITATION ON CAREGIVERS:

- 46.8% Sleep disturbances or insomnia
- 44.1% Anxiety
- 38.0% Depression

The burden is substantial, with 70% of caregivers of a person with agitation experiencing severe to very severe burden, compared to 56% of caregivers of a person not experiencing agitation.

To follow up, the A-LIST recently partnered on a second study focused on one-on-one interviews with caregivers to better understand this difficult symptom.



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