

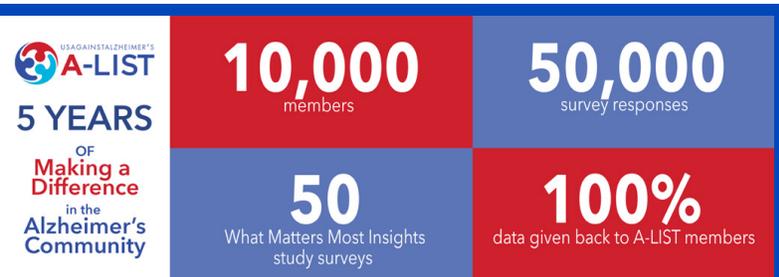
# CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. Our personal insights and preferences are turned into data and validate the collective experience of living with this disease and caring for a loved one. We call it the "science of us."

## The Pulse of the Community

### CELEBRATING 5 YEARS

Since 2016, UsAgainstAlzheimer's A-LIST has made sure that policymakers, researchers, healthcare providers, drug developers, insurers and others who serve this community understand and consider your insights when making decisions affecting those living with the disease and caregivers. **We are thankful to our 10,000 A-LIST members who are helping us make an impact!**



*“ Being part of a group that ensures my opinions are heard by researchers and policy makers is empowering. It won't bring my mother back, but it gives my journey purpose. ”*

- A-LIST Caregiver

### MAKING A DIFFERENCE

The data that comes from A-LIST research is driving changes that make life better for the entire dementia community. Here are some of the highlights.

### Paid Family and Medical Leave

In November, the U.S House of Representatives passed legislation that includes paid family and medical leave for people living with dementia and other serious medical conditions and their caregivers.

UsA2's Stephanie Monroe testified in October in support of the legislation, sharing her personal story as caregiver for her father. She also cited A-LIST research data quantifying the challenges faced by dementia caregivers of color to bolster her argument in favor of this critical legislation. It now must pass the Senate. Watch Stephanie's testimony [HERE](#).



*“ [It's most important to me to learn] how to be compassionate to individuals with dementia and how not to take their behavior personally. ”*

- A-LIST Caregiver

## Brain Health Equity

Communities of color are disproportionately impacted by Alzheimer's. African Americans are twice as likely as non-Hispanic Whites to develop Alzheimer's; Latinos are 1.5 times more likely. The dementia caregiving crisis is especially severe for women and communities of color who are more likely to have caregiving responsibilities and are at higher risk for dementia themselves.

To address these disparities, the A-LIST is working to increase diversity in our research. This includes developing and recruiting for research on the needs and priorities of African American and Latino caregivers. And we have forged strategic partnerships with researchers and organizations focused on brain health equity to help ensure people of color are sufficiently represented in our research. [Learn more here.](#)



### Supporting New Research on Priorities of Dementia Caregivers of Color

5 YEARS

OF  
Making a  
Difference  
in the  
Alzheimer's  
Community

- Text-based supports for Latino caregivers
- Challenges for Black and Latino caregivers
- Caregiver relationships with health care providers

“ I believe researching the authentic voice of the person living with dementia and the caregiver is powerful, especially the unique needs of a diverse population. This is why I partner with A-LIST so the voice of my community will be heard. ”

- Fayron Epps, PhD, RN, FAAN, Emory University School of Nursing

## Alzheimer's Therapies

In early 2021 the U.S. Food and Drug Administration (FDA) considered approval of Aduhelm, the first disease-modifying therapy for Alzheimer's. UsA2 made sure the voices of patients were heard by providing [A-LIST data](#) on the preferences of people who could benefit. It worked. The FDA indicated that patient views factored into the approval decision.



### Patient Preferences

5 YEARS

OF  
Making a  
Difference  
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Alzheimer's  
Community

84%

With mild cognitive impairment or mild Alzheimer's wanted FDA to factor in their willingness to take a possible treatment before efficacy's fully studied

63%

Said an Alzheimer's drug allowing current state of daily function for a year would offer some or significant benefit

78%

Said it's important to have access to an approved treatment allowing for additional year without worsening symptoms even with possible side effects in some people requiring management by a doctor

## Impact of Coronavirus Pandemic

The A-LIST COVID-19 longitudinal survey series is the only national, ongoing study on the impact of the coronavirus pandemic on the wider dementia community. The series revealed ongoing stress for caregivers, including those with a loved one living in long-term care. [Learn more here.](#) In May 2020, [UsA2 demanded](#) that the federal government and states require testing for staff and residents of long-term care communities. Later that year, the Centers for Disease Control and Prevention recommended that staff and residents be given priority for the vaccine.

In the ninth survey in our series fielded in November, results show that current caregivers are adapting to the stress of COVID-19 and restrictions resulting from it. For example, 50% of caregivers with a loved one in long-term care say their stress level has worsened because of the pandemic, down from 78% in February and March 2021. But caregiver stress remains high, and some people may face long-term impacts that require physician care.

This survey asked respondents about the pandemic generally. Seventy-nine percent said they believe the pandemic will never end. However, 47% believed that it will become manageable without restrictions; 32% believed that restrictions will become a routine part of life from now on. A minority believed that the pandemic is almost over (5%) or it will never end (3%); 13% were unsure.



### Caregivers with Loved-One in Long-Term Care

5 YEARS

OF  
Making a  
Difference  
in the  
Alzheimer's  
Community

72%

said stress levels higher during height of pandemic restrictions

**TOP STRESSORS:** Inability to assess health status of loved one, Concern about care provided by facility, Concern about facility's ability to manage the situation

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- A-LIST Caregiver

## COMING IN 2022

### *Lucidity in Dementia*

Sometimes people in the later stages of dementia who have lost the ability to express themselves have fleeting moments when they are able to communicate in some way. These are called lucid episodes. The A-LIST is collaborating with researchers from the Mayo Clinic's Kern Center for the Science of Healthcare Delivery to learn more about why lucid moments happen. Our early research shows that they can have a profound effect on caregivers and may be caused by various factors.

It's important to learn more in order to help caregivers prepare for and make sense of these lucid episodes. This will improve their interactions with their loved one living with dementia. Next year we will ask current caregivers about participating in a year-long study on lucidity. More information to come!

## THANK YOU!

Thank you to our partners and supporters, who are a key part of A-LIST success, including:

#### **AD PACE Executive Steering Committee Members:**

Leigh F. Callahan, PhD, UNC School of Medicine; Jim and Geri Taylor, Biogen, Boehringer Ingelheim, Home Instead Senior Care, LEAD Coalition, Lilly, Lundbeck, Otsuka, Takeda, Debra Lappin, Allison Martin and Sanjyot Sangodkar.

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## THANK YOU FROM THE A-LIST RESEARCH TEAM!

**Meryl Comer**, A-LIST Founder, UsA2 Board Member

**Virginia Biggar**, A-LIST Program Director, UsA2 Executive Director of Communities

**Terry Frangiosa**, A-LIST Principal Investigator

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