

## CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 8,000 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:

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

The COVID-19 pandemic has caused disruption, hardship and heartache for so many families dealing with Alzheimer's disease, frontotemporal, Lewy body and other forms of dementia. Since March, UsAgainstAlzheimer's A-LIST has fielded seven "What Matters Most" surveys to capture the experiences and insights of caregivers and people living with dementia. Their responses and comments offer candid insights into the Alzheimer's journey itself.

The results document and describe a growing crisis – caregivers coping with ongoing severe stress, people with dementia experiencing more-rapid cognitive decline, and devastating effects on nursing home residents, who have been more than 40% of COVID-19 deaths. Visitor restrictions mean long separations from family and too often these days, removing an important connection and for many families – a missed chance to say, "Goodbye."

"These survey findings speak to the abandonment felt by those affected by Alzheimer's disease and related disorders and how it is unconscionable to have been this ill-prepared," said Terry Fulmer, PhD, RN, FAAN and President of the John A. Hartford Foundation. "We have already seen the devastating effects of Hurricane Katrina, Superstorm Sandy and now COVID-19 as examples where those with Alzheimer's and other dementias and their caregivers are left to fend for themselves in the early days of catastrophes. There will be another crisis. Will we be ready? There can only be one answer and this heart wrenching survey data tell us all why."

#### Significant Stress and Effects on Caregivers

During the best of times, dementia caregivers face enormous challenges, including stress, isolation and financial hardship. This is especially true for caregivers of color given the disproportionate impact of Alzheimer's on people of color. The COVID-19 pandemic with its closures, restrictions and social distancing has exacerbated these outcomes.

In the A-LIST survey in October, 77% of caregivers said their stress level is higher since coronavirus restrictions were put in place. 86% of caregivers reported having one or more stress symptoms typically found in people experiencing severe stress. The surveys show consistently high rates of stress since March.

### Top stressors include:

- Vigilance/being 'super alert' (45%)
- Sleep problems (40%)
- Loss of interest in activities (34%)
- Difficulty concentrating (31%)
- Trouble experiencing positive feelings (29%)
- Irritable/angry behavior (25%)



**"On a daily basis, I feel more stress. This mental condition sometimes manifests in less sleep, more eating, more crying, and more muscular pains." – A-LIST Caregiver, June 2020**

In addition, 81% of current caregivers reported feeling negative emotions in their caregiver role, which is managed by talking with friends, prayer, meditation, listening to music, and a host of other strategies.

And one in five (20%) of caregivers say physical or mental health changes related to the COVID-19 pandemic have affected their ability to care for their loved one.

"Never has the convergence of major economic losses, dramatically higher vulnerability of health status for both care partner and patient, and devastating social isolation, come together so rapidly as a perfect storm – causing unpredictability and stress on a large

scale," said Dr. Sandra Bond Chapman, Founder and Chief Director of the Center for BrainHealth® at The University of Texas at Dallas.

### Significant Holiday Disruption Expected

COVID-19 infection rates are rising at an alarming rate across the country. Some regions are seeing new shutdowns and other restrictions. And public health and other officials are pleading with the public to stay home for the holidays. A-LIST members predicted this turn for the worse with 90% of current caregivers – and 84% of all respondents – saying in October that they expected disruption of their holiday plans. Two-thirds of caregivers believed that the impacts would be significantly negative.



**"No indoor parties, no big family meals, no sitting in the living room opening presents and no indoor restaurant meals with groups of friends. It won't be stress as much as sadness. I'll miss entertaining and gifting my kids and grandkids." – A-LIST Caregiver, October 2020**



**"At the same time as my dad is rapidly declining, my husband is struggling with depression and memory issues to the point of losing his job after exhausting FMLA (Family and Medical Leave Act). I am stretched very thin and feel drained and overwhelmed." – A-LIST Caregiver, June 2020**

### Uncertainty of Plans if Caregiver Becomes Sick with COVID-19

Throughout the survey series, consistently about three-fourths of those taking care of a person with Alzheimer's at home did not have a backup plan should the caregiver get COVID-19.

To address these concerns, UsAgainstAlzheimer's compiled resources and advice to help families plan ahead before getting sick to avoid more significant stress later on. You can find the resources [here](#).



**"I honestly don't know what would happen if I become sick; we would just have to struggle through as best we can." – A-LIST Caregiver, August 2020**

## Memory Declines Seen for those with Dementia

Starting in July, we asked survey respondents if memory or behavior had changed for those with dementia since coronavirus restrictions and closures were put into place. Throughout three surveys, caregivers and people with dementia alike reported greater than usual cognitive decline. Consistently just over 40% of survey respondents with MCI, Alzheimer's or another dementia believed their cognition had declined since coronavirus restrictions and closures have been in place. Caregivers have seen even greater effect on cognition, with 70% of caregivers reporting over recent months a decline in their loved ones' memory or behaviors.

## Concerns about Family Members in Long-Term Care Facilities

More people are dying from Alzheimer's and other forms of dementia during the COVID-19 pandemic, according an [analysis by the Washington Post](#). In



**"The little social contact I had before has now almost entirely diminished. Seem to be more forgetful and harder to say what I mean." – A-LIST Member with Dementia, May 2020**



**"Mom's isolation has caused her to have delusions...it's the lack of people contact and the constant news talking about the virus."**

– A-LIST Caregiver, June 2020

addition, nearly half of all long-term care facility residents are living with Alzheimer's or another dementia. The [rising cases](#) and deaths in long-term care make this group one of the most vulnerable to COVID-19 in the country, especially [nursing homes with a significant number of Black and Latino residents](#).

When the pandemic began in March, 74% of survey respondents said they were not allowed to visit family members in long-term care. That number has gone down as COVID-19 testing has increased and nursing homes and families have become more adept at managing family visits. By October, 42% of caregivers said they were unable to see loved ones.

Caregivers who have loved ones with dementia in long-term care facilities have continued to feel higher stress because of visitation restrictions and challenges getting information about their loved one. But that number has dropped as visits increase with 50% in October saying that their stress level is worse now as it relates to care of their loved one in an assisted living facility. That number is down from 75% in March.

The top stressors of caregivers with loved ones in assisted living facilities have been consistent over six surveys:

- The inability to know/accurately assess health status (71%)
- Concern about facility's ability to adequately care for their loved one (46%)

## Long-Term Care



**21%**

of caregivers in October were less confident about the level of care for their loved one since the coronavirus restrictions were put into place, a decrease from 35% in March.



**58%**

said they had heard of cases of COVID-19 in the facility at the time of this survey, seemingly leveled-off from the increases over the past several surveys



**Nearly two-thirds**

of caregivers (58%) said that their loved one has been tested for COVID-19



**92%**

supported required COVID-19 testing of all residents and staff, with the remainder unsure or having no opinion



**“My greatest fear was that my mom would forget me. But the deterioration that I notice during backyard visits has really been amazing. She needs a lot of help to walk which she never did. It’s been excruciating. That’s the best word I can come up with. And the guilt is overwhelming.”**

**– Loretta Veney, Caregiver Advocate**

## UsAgainstAlzheimer’s Takes Action

In May – armed with your feedback in these surveys – UsAgainstAlzheimer’s called on the federal government and the nation’s governors to require immediate and comprehensive COVID-19 testing of all residents and staff in long-term care facilities to control the spread of the coronavirus among these highly

vulnerable residents. Read our letter to U.S. Health and Human Services Secretary Alex M. Azar [here](#) and our letter to the National Governor’s Association [here](#).

UsAgainstAlzheimer’s was pleased to see an advisory committee for the Centers for Disease Control and Prevention recommend in early December that nursing home residents and staff be given priority for the new coronavirus vaccine.



**“My mother feels abandoned, scared, and confused and I cannot be there to help.”**

**– A-LIST Caregiver, June 2020**



**“Testing some patients and staff is not sufficient. Much of the challenge in controlling COVID-19 transmission results from asymptomatic transmission of the virus.”**

**– Russ Paulsen, Chief Operating Officer, UsAgainstAlzheimer’s**

## Caregivers Share Coping Advice

While caregivers are more stressed and anxious during this crisis, they have also generously shared advice on managing these feelings during this deeply uncertain time. In April, we asked survey respondents to share suggestions and coping tips.

Suggestions included ways to stay connected with family and friends, maintain routines, find positive things in life, exercise, seek-out and accept spiritual and emotional support, and laugh whenever possible. You can read their complete advice [here](#).



“Do everything you can to keep yourself and your loved one connected to those they love. Use creative ways to give your loved one structure to their day, that’s as close as possible to their prior routine. It seems this is not the time for them to learn anything new.”

– A-LIST Member, April 2020

“Be open to ideas that don’t sound promising at first by may turn out to be positive. Come up with a mantra that we are not separate but safe.”

– A-LIST Member, April 2020

## Preparing for the Next Crisis

The COVID-19 pandemic has exposed the cracks in health and support systems for individuals and families living with Alzheimer’s disease and other forms of dementia. And it has shined a bright light on the day to day challenges and inequities that already existed.

“I dread the coming winter when we all go back inside and have to figure out how to keep each other busy and engaged and challenged. And not become totally isolated. That is my fear.”

– Emily Ingalls, FTD Caregiver Advocate

UsAgainstAlzheimer’s held a Town Hall discussion with national leaders during our 2020 National Alzheimer’s Summit to talk about solutions. Watch the Town Hall discussion [here](#).

In her Town Hall remarks, The Honorable Michelle Lujan Grisham, Governor of New Mexico, whose mother has dementia, said a multi-pronged approach is needed to combat COVID-19. This includes better preventative strategies, such as fewer people living in long-term care facilities, improved back up and access to critical care for families, and greatly improved public health measures and infection control.

“Let’s attack this pandemic and solve it. Let’s take care of our families and loved ones who are in long-term care and at home,” Governor Lujan Grisham said, adding, “Let’s cure Alzheimer’s. Let’s prevent Alzheimer’s and chronic conditions.”

## Finding Strength, Patience and Satisfaction

The coronavirus pandemic has been an unprecedented and long-lasting disruption in the lives of families across the nation, and people found themselves doing things they didn't know they were capable of doing.

A-LIST members shared the one thing they have learned about themselves during the last nine months. Respondents offered personal reflections on relationships, resilience, isolation and religious faith. Read their complete responses [here](#).

 **"Since my husband's Alzheimer's keeps progressing at a seemingly faster pace, [I've learned] how I can keep dealing with it and find work arounds/lowering my expectations. My friend says I'm a rock."**  
– A-LIST Caregiver, October 2020

 **"I actually like to be alone and I have been able to give myself permission to not do everything - that my "good enough" is actually ok. It has surprised me. But I am also lonely, and I crave conversation with someone who is able to have a conversation. We are alone, the two of us, and my husband can't hold a conversation. The loneliness scares me sometimes."**  
– A-LIST Caregiver, October 2020



**"That I can cope with this pandemic because I have to."**

– A-LIST Member, October 2020



**"I value the community at my mother's residence more than I realized, now that I'm mostly excluded."**

– A-LIST Caregiver, October 2020

## Thank You from All of Us to All of You

UsAgainstAlzheimer's and the A-LIST research team wish to thank the members of the A-LIST who shared their personal insights over the last nine months. This work was not possible without you.

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## Publications

Click [here](#) to find summaries of the seven A-LIST What Matters Most Insights COVID-19 impact surveys, blog posts and related publications.



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