

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 7,700 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:

Coronavirus Crisis Impacts on Alzheimer's Community

A survey by the UsAgainstAlzheimer's A-LIST® shows that the COVID-19 coronavirus crisis is causing more stress, isolation and financial concerns for members of the Alzheimer's community, especially for family caregivers.

The coronavirus outbreak has resulted in widespread social distancing, isolation and quarantine orders, business closings, and growing numbers of cases throughout the United States. This has exacerbated the isolation and stress that dementia caregivers already feel. Day programs for people with dementia, which normally provide respite for caregivers, have been canceled. Some family caregivers are not receiving home health aides in order to maintain social distancing for themselves and their loved ones. And many caregivers with loved ones in memory care or assisted living feel even additional stress because they can't visit them in person or communicate easily.

This survey, the first in an ongoing series, provides insights from the Alzheimer's community into challenges and concerns resulting from the coronavirus crisis. **These survey results help UsAgainstAlzheimer's to serve as a strong, unified voice advocating for our community.**

The full survey results can be seen [here](#).

Biggest Effects on Caregivers

Nearly three-quarters of people taking care of family members with dementia at home (family caregivers) say they are unsure what would happen to their loved one if they got sick with COVID-19.

In addition, 33% of caregivers said they were unsure what they would do if their loved one with Alzheimer's became sick. The survey also found that coronavirus restrictions at assisted living facilities mean that many family members are unable to see or assess the health status of their loved one(s).

"Alzheimer's family caregivers are frontline healthcare workers in their homes, and if they get sick, what happens to the patient? COVID-19 has only further exacerbated the daily challenges in their lives," said Meryl Comer, a long-time caregiver for her husband and mother and UsA2 founding Board member.

Earlier A-LIST surveys showed that family caregivers [already had higher levels of loneliness and isolation](#), and the coronavirus restrictions have made them feel even more isolated from family and friends, and more stressed and concerned about their future financial health.

Coronavirus Crisis Impacts on Alzheimer's Community

CAREGIVER SURVEY FINDINGS



82%
of caregivers say their **STRESS WAS HIGHER** now because of the coronavirus



74%
of caregivers were **MORE CONCERNED ABOUT THEIR FINANCIAL HEALTH** and their family's finances than before the coronavirus



37%
said the shelter-in-place restrictions were creating **ADDITIONAL TENSION** for their family about keeping their loved one at home



24%
said it was **HARD** for them or another family member to be close to a loved one with Alzheimer's **24 HOURS A DAY**



32%
of caregivers wanted **ADDITIONAL GOVERNMENT SUPPORT** for their caregiving, and 18% wanted help with Medicare, Medicaid or other insurance benefits



31%
of caregivers said they were **GETTING LESS INFORMATION** than they needed to provide care and support to a loved one, with 64% getting sufficient information

In Their Own Words



"My husband is nearly bed bound now. I have my caregivers less often, so I am not keeping up with outdoor responsibilities & exercise. I am unable to spend time doing hobbies & cannot have friends over for game nights which is a stress break for me. I cannot go to a support group I enjoy. I cannot run out and pick up supplies for a home improvement project to keep busy inside."



"I am not able to take my wife out in public or to the grocery store based upon her dementia and uncontrolled need to greet/hug/love on strangers."



"My husband has become significantly more confused and his language has significantly deteriorated in last 2-3 weeks, adding stress on me."



"Change of routine and no social interactions has my mom really out of sorts. Lack of understanding means she's unwilling to take precautions like washing hands. Showers are impossible. Can't leave apartment as she wants to touch everything. Food and medication are an issue."

Heightened Stress about Loved Ones in Assisted Living Facilities

Survey respondents who have loved ones with Alzheimer's or dementia in assisted living communities report that they are more stressed because of visitation restrictions at the facilities.



"I can't visit either of my Dementia affected parents. I've had difficulty contacting their providers to order medicine and make changes to their meds."



"I can only visit my husband standing at window in all sorts of weather, kneeling on concrete to get in his line of vision."

Caregivers Share Coping Advice

While caregivers said they were more stressed and anxious during this crisis, they were also generous with advice on how to manage these feelings during this deeply uncertain time. The survey asked respondents to share suggestions and coping tips. You can find their advice in this [blog post](#).



"Keep in touch in every way you can – phone calls, social media, Zoom, FaceTime, texting. Check on others who maybe isolated as well. Look outside yourself."



"Do gardening, clean out your garage, walk your dog, visit a park. Nature is a great healer!"



Nearly 3/4

(74%) said they were unable to see their loved one because of virus-related visitation restrictions.



67%

say they were **UNABLE TO ASSESS THE HEALTH STATUS** of their loved one



35%

were **LESS CONFIDENT ABOUT THE LEVEL OF CARE** for their loved one



33%

said they were **MORE CONFIDENT ABOUT CARE** of their loved one, and 37% felt **RELIEVED** because they do not believe they could have managed their care at home

The 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. Here are some of the suggestions – we hope you find them helpful and inspiring.



"My sister and I don't try to explain COVID-19 to my father because he won't understand and won't remember. We tell him every day that we are both sick and the doctor wants us to stay at home, so we don't infect others. It's a brand-new story for him every day. We just pray that the Lord comfort and care for my dad and the other memory care residents on a daily basis as they adjust to this new way of life."

COVID-19 Impacts on Broader Alzheimer's Community

The A-LIST survey found that the coronavirus crisis was causing greater stress, isolation and financial concerns across the entire group of respondents, which also included people living with the disease, former caregivers, people who believe they are at significant risk of developing Alzheimer's, and those interested in brain health and advocacy.

As of late March, when this survey was fielded, nearly 8 in 10 (79%) respondents did not report many current effects of the COVID-19 isolation orders on their ability to work and provide financially for their families. In large part, people living with Alzheimer's and their caregivers are older and retirement-eligible, which could account for the generally low impact on employment reported among survey participants. At that time, about 8% of overall survey respondents reported reduced hours of work, 6% said they were forced to take unpaid time off, and 2% said they were required to take vacation.



76%
said their **STRESS IS HIGHER**, including 18% who said it is significantly higher



57%
felt **MORE ISOLATED**



72%
were **MORE CONCERNED ABOUT THEIR FINANCES** and their family's finances, including 27% who were **MUCH MORE** concerned

COVID-19 Resources

For latest news and guidance on COVID-19, check the best sources of reliable information from government and health leaders:

- [Centers for Disease Control \(CDC\) COVID-19 website for prevention information, updates, and Frequently Asked Questions](#)
- [CDC information in Spanish](#)
- [National Alliance for Hispanic Health](#)
- Your own state Health Department

About this Survey: The survey, taken March 25-30, 2020 by the UsAgainstAlzheimer's A-LIST, had 807 responses overall from people living with Alzheimer's or dementia, current or former caregivers, people with a significant likelihood of developing the disease, and those interested in brain health or Alzheimer's advocacy. Current caregivers were the largest group, with 198 responses, with a subset of 52 respondents who said they had a loved one in an assisted living facility. In some questions, such as a list of a range of coronavirus effects, respondents could select more than one response.

About the A-LIST: The UsAgainstAlzheimer's A-LIST is a growing online community of more than 7,700 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 contribute to IRB research which 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.



Make your opinions count for research.

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