

UsAgainstAlzheimer's

UsA2 A-LIST Survey: Significant Coronavirus Impacts on Alzheimer's Caregivers

More Isolation, Higher Stress and Increased Concerns about COVID-19 Infections

The coronavirus crisis is having significant effects on caregivers for people living with Alzheimer's and dementia, raising uncertainty and concerns about who would take care of a loved one if the caregiver was infected with the virus and increasing [already high levels of isolation](#) and stress, according to a new survey by UsAgainstAlzheimer's A-LIST®.

The survey results give insights into the challenges and concerns of the broad Alzheimer's community of patients, caregivers and others from the COVID-19 coronavirus, which has resulted in widespread social distancing, isolation and quarantine orders, business closings and growing numbers of cases throughout the United States.

Greatest Impacts Felt by Current Caregivers – The survey results found the highest levels of stress, isolation from friends and activities, financial concerns and health worries from the coronavirus crisis among current Alzheimer's caregivers.

- 71% said they were unsure of **what would happen to a loved one with Alzheimer's or dementia** if the caregiver gets sick with the COVID-19 coronavirus, and 33% were unsure what to do if their loved one with Alzheimer's or dementia becomes sick.
- 82% percent of caregivers say their **stress** is higher now because of the coronavirus.
- 74% of caregivers are more concerned about their **financial health** and their family's finances than before the coronavirus.
- 37% said the shelter-in-place for their family was creating **additional tension about keeping the loved one at home**, and 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 want **additional government support for their caregiving** and 18% want help with Medicare, Medicaid or other insurance benefits.
- 31% of caregivers say they are **getting less information than they need to provide care** and support to a loved one, with 64% getting the information they need

Heightened Stress about Care of Loved Ones in Assisted Living Facilities – A smaller set of survey respondents who have loved ones with Alzheimer's or dementia in assisted living facilities have stress and concerns because of visitation restrictions at the facilities.

- 74% are **unable to see their loved one** because of virus-related visitation restrictions.
- 75% say their **stress** levels are significantly higher
- 67% say they are **unable to assess the health** status of their loved one
- 35% are **less confident about the level of care** for their loved one.
- One the other hand, 33% say they are **more confident** about care of their loved one and 37% are **relieved** because they do not believe they could have managed the care for their loved one at home.

Methodology: The survey, taken March 25-30 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 made up the largest group with 198 responses, including a subset of 52 respondents saying they had a loved one in an assisted living facility.

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Key Findings from the Entire Survey Group

The survey found more stress, isolation and financial concerns for the future among the entire group of respondents that includes people living with the disease, former caregivers, people at significant likelihood of developing the disease, and those interested in brain health and advocacy.

- 76% say their stress is higher, including 18% saying it is significantly higher.
- 57% feel more isolated
- 72% are more concerned about their finances and their family's finances, including 27% who are much more concerned.

Limited Impact on Work: Survey respondents so far were not reporting many effects on their ability to work and provide financially for their families to date, with 79% reporting no effect to date. In large part, people living with Alzheimer's and their caregivers are older and retirement-eligible, which could account for the low job impacts among survey participants. About 8% of the overall survey respondents reported reduced hours of work, 6% said they had to take forced unpaid time off, and 2% said they were required to take vacation.

Sources of Coronavirus Information: The survey respondents say they are getting information about the coronavirus from television (62%) news sites (34%), state and local government sites (33%), non-government health sites (21%), and federal government sites (20%).

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