



## UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for Survey 2 – April 2020

### Significant Effects on Current Caregivers (197 Respondents)

- 92% percent of caregivers say their **stress** is higher now because of the COVID-19 coronavirus
  - 10-point increase since the [March survey](#) (Survey #1)
  - 26 points higher than the group of survey respondents generally interested in brain health
  - More than a third (35%) of caregivers said their stress was significantly higher – 13 points higher than any other survey group
- 80% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress**
  - 7 points higher than the overall group of respondents.
  - The top-reported caregiver stressors include
    - Sleep problems (36%)
    - Vigilance/being 'super alert' (34%)
    - Difficulty concentrating (29%)
    - Irritable/angry behavior (25%)
    - Trouble experiencing positive feelings (23%)
- 73% of those taking care of people with Alzheimer's disease at home are **unsure what would happen to their loved one if they got sick** with COVID-19
- 42% of caregivers are unsure what to do if their **loved one with Alzheimer's became sick**
  - 9-point increase since the March survey
- 74% of caregivers feel more **isolated than before coronavirus restrictions**
- 61% of caregivers are more concerned about their **financial health** and their family's finances than before the coronavirus
  - 13-point decline since March (the March survey was taken after major declines in the stock market and the beginning of widespread stay-at-home orders)
- 29% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**
  - 8-point decline from last month
  - 34% said it was hard for them or another family member to be close to a loved one with Alzheimer's 24 hours a day, a 10-point increase since March
- 40% of caregivers with loved ones at home would **consider assisted living facilities for their loved one** if
  - They can't provide adequate physical support (24%)
  - Their loved one is increasingly confused (21%)
  - Their loved one is increasingly agitated (18%)
- 20% of caregivers want **government/financial support** such as food stamps or unemployment insurance

### Concerns about Care of Loved Ones in Assisted Living Facilities

A smaller set of 46 survey respondents who have loved ones with Alzheimer's or another dementia in assisted living facilities have higher stress because of visitation restrictions and challenges getting information about their loved one.

- 91% were **unable to see their loved one** because of virus-related visitation restrictions
- 72% said their stress levels were higher
  - Including 33% who said their stress was significantly higher
- Top stressors of caregivers with loved ones in assisted living facilities
  - Inability to know/accurately **assess health status** (74%)
  - Concern about facility's ability to adequately care for their loved one (46%)
  - Concern about facility's ability to manage the situation (41%)
- 41% are **less confident about the level of care** for their loved one
- 15% of caregivers said they are concerned enough to consider removing their loved one from the facility
- 17% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey (April 17-21)

### **Limited Financial Impact of COVID-19 to Date**

- 17% of overall respondents reported current effects of the coronavirus 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 low job impacts among survey participants. About 9% of the overall survey respondents reported reduced work hours, 6% had to take forced unpaid time off, and 1% were required to take vacation.

**Survey Methodology:** The survey, taken April 17-21, 2020 by the UsAgainstAlzheimer's A-LIST®, had 750 responses overall from people living with Alzheimer's or another dementia, current and 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 197 responses, with a subset of 46 respondents who said they had a loved one in an assisted living facility. In some questions, such as a list of a range of effects of the virus, respondents could select more than one response.

*The UsAgainstAlzheimer's COVID-19 survey series is supported in part by the Eisai USA Foundation, and Cohen Veterans Bioscience provided input on survey design and analysis.*