

UsAgainstAlzheimer's

UsAgainstAlzheimer's Survey #7 on COVID-19 and Alzheimer's Community Summary of Findings October 2020

UsAgainstAlzheimer's fielded its seventh survey on the effects of COVID-19 on people affected by Alzheimer's disease and other dementias from October 8-14, 2020. Below are key findings.

Significant holiday disruption from COVID-19 restrictions anticipated for caregivers and all survey respondents

- 90% of current caregivers – and 84% of all respondents – **expect negative impacts to their upcoming holiday plans** such as fewer family interactions, holiday traditions or parties, with two-thirds of caregivers thinking that the impacts would be significantly negative. *“Eating holiday meals alone really saddens me and our church gift exchange won't happen.”*
- 44% of caregivers said that their mood has worsened over the past two weeks; this is 13 points higher than the overall group, where 31% said that their mood had worsened. *“All in all, stress is number 1 in what's going on right now. We stay inside all the time.”*

A third of caregivers and overall respondents remain unsure about a COVID-19 vaccine

- 54% of current caregivers (and 59% of the overall cohort) intend to get a COVID-19 vaccine, once one is available. About 31% of caregivers (30% of overall cohort) say they are unsure about whether they will get a COVID-19 vaccine. These findings show that the Alzheimer's community, with many higher risk individuals, seem more willing to get a new COVID-19 vaccine than surveys of the general public show.
- 86% of current caregivers (86% of overall cohort) intend to get a flu shot this season.
- 50% of caregivers with loved ones in a long-term care community say they intend to request a COVID-19 vaccine for their loved one, once a vaccine is available and if they have robust safety and efficacy data. In comparison, 88% of these caregivers intend to request a flu shot for their loved one in a long-term care community.

Declines Seen in Memory and Behavior for those with Dementia during COVID-19 Closures and Isolation

- Since coronavirus restrictions, closures, and isolation have been in place, 70% of caregivers observed a **decline in their loved ones' memory or behaviors**. This percentage has been at about two-thirds for three consecutive months. Another 29% of caregivers said there had been no change in the memory or behaviors in their loved one.
- Of the 38 respondents in October who have been diagnosed with mild cognitive impairment, Alzheimer's or dementia, 42% believed their cognition has declined somewhat; another 5% said they had experienced significant declines. Another 47% said there had been no change.

Significant Stress and Effects on Current Caregivers over 6 months (145 respondents)

- 77% percent of caregivers say their **stress** level is higher since coronavirus restrictions were put in place. This is consistent in the surveys since March.
- 86% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress**. The surveys have revealed these consistently high rate of stressors for caregivers for six months.
 - Top-reported caregiver symptoms associated with stress among the total group remain largely unchanged. (Respondents could select more than one choice and percentage is of total caregivers.) **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%)
- 81% of current caregivers have felt negative emotions in their caregiver role, which is managed by speaking with friends, prayer/meditation, listening to music and a host of other strategies.
- 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**.
- 75% of caregivers felt **more isolated** than before coronavirus restrictions.
- 60% of caregivers felt more lonely than before coronavirus restrictions.
- 32% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**; 35% 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 need for more direct care: 27% of current caregivers say that they have less family support for caregiving, while 20% have less access to adult day care.

Continued Uncertainty of Plans if Alzheimer's Caregiver Becomes Sick with COVID-19

- 75% of those taking care of people with Alzheimer's disease at home were unsure what would happen to their loved one if the caregiver became sick with COVID-19. This is similar to most previous surveys, which have averaged above 70%.
- 29% of caregivers were unsure what to do if their loved one with Alzheimer's became sick.

Concerns about Care of Loved Ones in Assisted Living Facilities (24 respondents)

A set of 24 respondents who reported having loved ones with Alzheimer's or another dementia in assisted living facilities continue to have higher stress because of visitation restrictions and challenges getting information about their loved one. The July and September surveys showed that more people are able to visit loved ones in a long-term care community. Growing numbers of COVID-19 tests and more COVID-19 cases in the communities where their loved ones live are being reported in this survey.

- 42% were **unable to see their loved one** because of virus-related visitation restrictions. The October survey results show the continuing loosening of visitation restrictions at long-term care communities.
- 58% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey, seemingly leveling 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**; 25% said their loved one had not been tested, and 17% didn't know.
- Half (50%) noted that their stress level is worse now as it relates to care of their loved one in an assisted living facility.
- 92% supported **required COVID-19 testing** of all nursing home residents and staff, with the remainder unsure or having no opinion.
- Top stressors of caregivers with loved ones in assisted living facilities include:
 - Inability to know/accurately **assess health status** (71%)
 - Concern about facility's ability to adequately care for their loved one (46%)
- 21% are **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place.

Survey Methodology: The survey, taken October 8-14, 2020 by the UsAgainstAlzheimer's A-LIST®, had 567 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. Of the total respondents, 523 described their status. Current caregivers were the largest group with 145 responses. Of the 142 caregivers completing the survey, a subset of 24 respondents who said they had a loved one in an assisted living facility. Of caregivers, 10% were care partners to individuals with mild Alzheimer's disease or dementia, 53% were care partners to those with moderate disease and 34% oversaw severe cases (with only 3% unsure). 38 individuals with Alzheimer's disease or Mild Cognitive Impairment also took the survey. This research is overseen by an Institutional Review Board (IRB.)

The UsAgainstAlzheimer's COVID-19 survey series is supported in part by the Eisai USA Foundation, naviHealth and Biogen. with research support from Cohen Veterans Bioscience.