

UsAgainstAlzheimer's Survey #8 on COVID-19 and Alzheimer's Community February/March 2021 Summary of Findings

UsAgainstAlzheimer's fielded its eighth survey on the effects of COVID-19 on people affected by Alzheimer's disease and other dementias from February 26 – March 3, 2021.

High Vaccine Acceptance

Vaccine acceptance among the survey respondents (n=647) is higher than the general population, with only 8% saying they are unwilling to get or unsure about getting the vaccine.

- 56% of current caregivers (n=147) have received at least one dose of the vaccine (similar to the overall survey sample)
- Those current caregivers who have not gotten the vaccine cited the following reasons: not yet eligible (41%); tried to schedule appointment but not yet able (23%); have scheduled an appointment (11%); not planning to get vaccine/unsure (25%)
- 100% of caregivers with a loved one in long-term care facilities (n=27) noted that their loved one has been vaccinated

Significant Stress and Effects on Current Caregivers over 12 months

- **77% percent of caregivers say their stress level is higher since coronavirus restrictions were put in place.** This is similar to prior surveys since April 2020 and speaks to long-term increased stress for this group.
- 84% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress**, indicating one year of consistently high rate of stressors that caregivers are experiencing
 - Top-reported caregiver symptoms associated with stress include:
 - Vigilance/being 'super alert' (44%)
 - Loss of interest in activities (40%)
 - Trouble experiencing positive feelings (31%)
 - Sleep problems (30%)
 - Difficulty concentrating (27%)
 - Irritable/angry behavior (21%)
- 80% of current caregivers have felt negative emotions in their caregiver role, which is managed by speaking with friends (61%), prayer/meditation (50%), exercise/yoga (44%), listening to music (39%) and a host of other strategies.
- 22% of caregivers say physical or mental health changes related to the COVID-19 pandemic have affected their **ability to care for their loved one**
- 81% of caregivers felt **more isolated** than before coronavirus restrictions; 57% of caregivers felt **more lonely** than before coronavirus restrictions
- 41% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**; 38% said it was hard for them or another family member to be close to a loved one with Alzheimer's 24 hours a day
- Current caregivers note that they need and cannot get access to support groups (24%) and home health aides (18%)

Concerns about Care of Loved Ones in Assisted Living Facilities (27 respondents)

A set of 27 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. While caregivers noted that most of their loved ones in assisted living have been tested and all of them have been vaccinated, the growing length of time that individuals have been unable to visit their loved ones, combined with an inability to accurately know or assess their health status, appears to be resulting in lower confidence in care versus the previous survey in October 2020.

- 63% were **unable to see their loved one** because of virus-related visitation restrictions
- Over 3/4 (78%) noted that their stress level is worse now as it relates to care of their loved one in an assisted living facility – an increase of 28 points since the October 2020 survey
- 93% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey
- Top stressors of caregivers with loved ones in assisted living facilities include:
 - The inability to know/accurately **assess health status** (85%)
 - Concern about facility's ability to adequately care for their loved one (52%)
- 37% are **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place
- Nearly all caregivers (96%) said that their **loved one has been tested for COVID-19**

More severe 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, nearly three-quarters (72%) of caregivers observed a **decline in their loved ones' memory or behaviors**. This includes 31% who reported a significant decline. Another 28% of caregivers said there had been no change in the memory or behaviors in their loved one.
- Of the 38 patient respondents – those diagnosed with mild cognitive impairment, Alzheimer's or dementia – 42% said they believe their cognition has declined somewhat; another 5% said they had experienced significant declines; 45% said there had been no change; and 7% said that they improved somewhat.

Survey Methodology: The survey, taken February 26 – March 3, 2021, by the UsAgainstAlzheimer's A-LIST®, had 647 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, 599 described their status. Former caregivers were the largest group with 153 responses, followed by current caregivers with 147 responses. Of the 143 caregivers completing the survey, a subset of 27 respondents who said they had a loved one in an assisted living facility. Thirty-eight individuals with Alzheimer's disease or Mild Cognitive Impairment also took the survey. This research is overseen by an Institutional Review Board (IRB).

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