



UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for June 2020 Survey (Survey #4)

UsAgainstAlzheimer's fielded its fourth survey on the effects of COVID-19 on people with Alzheimer's disease or another dementia, from June 9-14, 2020. A summary of findings follows.

Significant Effects on Current Caregivers (176 respondents)

- 77% percent of caregivers said their **stress** level was higher since coronavirus restrictions were put in place
 - Similar rate (4-point decrease) to the May survey (Survey #3), and 15-point decrease since the April survey (Survey #2)
- 82% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress** – down 6 points from May (Survey #3), and similar to the 80% of caregivers who reported symptoms in April (Survey #2)
 - Top-reported caregiver symptoms associated with stress, among the total group, remain largely unchanged, despite the reduction in people experiencing stress symptoms, which include (**respondents could select more than one answer and percentage is of total caregivers*):
 - Sleep problems (41%)
 - Difficulty concentrating (36%)
 - Vigilance/being 'super alert' (33%)
 - Trouble experiencing positive feelings (31%)
 - Loss of interest in activities (31%)
 - Irritable/angry behavior (25%)
- 31% of caregivers said physical or mental health changes related to the COVID-19 pandemic and isolation have affected their **ability to care for their loved one**, up 6 percentage points from the May survey
- 28% of caregivers said they needed but could not access **support groups**
- 18% needed but could not access **home health aides**
- 75% of caregivers said they were more likely (compared to before restrictions) to:
 - Take better care of themselves (56%)
 - Bring added care support into the home (27%) – up 8-points since May
 - Ask doctor to change loved one's medication (25%) – up 10-points since May
 - Ask doctor for medication for their own stress level and anxieties (16%)
(**caregivers could select more than one answer*)
- 71% of those taking care of people with Alzheimer's disease at home were unsure what would happen to their loved one if they (the caregiver) got sick with COVID-19
- 38% of caregivers were unsure what to do if their loved one with Alzheimer's became sick
- Nearly 4 in 10 (37%) of at-home caregivers are/were (until coronavirus restrictions went into place) using a home care aide for the care of their loved one
- 69% of caregivers felt **more isolated** than before coronavirus restrictions (slightly lower than May (5-point decrease)
- 43% of caregivers were more concerned about their **financial health** and their family's finances than before the COVID-19 pandemic closures, a 12-point decline from May and an 18-point decline compared to the April survey
- 33% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**

- 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
- 7% of caregivers wanted **government/financial support** such as food stamps or unemployment insurance
- 7% of caregivers wanted paid sick and family leave for caregivers of people with Alzheimer's or another dementia
- 72% of caregivers said that no additional government/financial support was necessary

Concerns about Care of Loved Ones in Assisted Living Facilities (34 respondents)

A smaller set of 34 respondents who reported having loved ones with Alzheimer's or another dementia in an assisted living facility had 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
- Over two-thirds (68%) noted that their stress level was worse relating to care of their loved one in an assisted living facility
- 94% 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 included:
 - Inability to know/accurately **assess health status** (85%), up 21 points since the May survey, but up only 11 points compared to the April survey
 - Concern about facility's ability to adequately care for their loved one (47%)
 - Concern about facility's ability to manage the situation (35%)
- 44% were **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place, up 8-points from the May survey
- 15% were concerned enough to consider removing their loved one from the facility
- Caregivers were willing to consider the following safeguards when visiting their loved one in a long-term care community: wearing personal protective equipment (94%); socially distanced visiting (74%); getting tested for COVID-19 before visiting (59%); video visiting as an alternative to in-person visiting (59%); paying for COVID-19 testing before visiting (41%). No caregivers (0%) said they expected the need for coronavirus restrictions to end soon
- 50% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey (June 9-14), up 19-points since the May survey, and 33 points higher than the April survey
- Nearly half of caregivers (47%) said that their loved one had been tested for COVID-19; 35% said their loved one had not been tested, and nearly one in five (18%) didn't know

Concerns by People Diagnosed with MCI, Alzheimer's or Other Dementia (50 respondents)

A smaller set of 50 respondents, who identified themselves as having been diagnosed with mild cognitive impairment, Alzheimer's, or another dementia, reported having higher stress levels, but not as high as caregivers

- 52% had somewhat or significantly more stress than they did before coronavirus restrictions went into place, 13 points lower than May
- 40% of respondents with a diagnosis believed that their care partner's stress level was higher as a result of the coronavirus outbreak

- Survey comments showed increased anxiety and loneliness among diagnosed individuals
- About 1/3 (34%) of individuals with a diagnosis wanted support but could not get it since the coronavirus crisis started, including:
 - Pastoral care/religious services (13%)
 - Support groups (11%)
 - Family support (11%)

Survey Methodology: The survey, taken June 9-14, 2020 by [UsAgainstAlzheimer's A-LIST®](#), had 682 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, 682 described their status. Current caregivers were the largest group, with 190 responses. Of the 176 caregivers completing the survey, a subset of 34 respondents said they had a loved one in an assisted living facility. This research is overseen by an Institutional Review Board (IRB).

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