

UsAgainstAlzheimer's

UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for May 2020 Survey (Survey #3)

UsAgainstAlzheimer's fielded its third survey on the effects of COVID-19 on people affected by Alzheimer's disease and other dementias from May 8-13, 2020. A summary of findings follows.

Significant Effects on Current Caregivers (176 respondents)

- 81% percent of caregivers say their **stress** level is higher - since coronavirus restrictions were put in place.
 - 11-point decrease since the [April survey](#) (Survey #2) but similar to levels in the [March survey](#) (Survey #1)
- 88% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress** - up 8 points from April (Survey #2)
 - Top-reported caregiver symptoms associated with stress among the total group (note that respondents could select more than one choice) include:
 - Sleep problems (38%)
 - Difficulty concentrating (34%)
 - Trouble experiencing positive feelings (31%)
 - Loss of interest in activities (31%)
 - Vigilance/being 'super alert' (29%)
 - Irritable/angry behavior (25%)
- 25% of caregivers say physical or mental health changes related to the COVID-19 pandemic and isolation have affected their **ability to care for their loved one**
- 26% of caregivers say they need and cannot get access to **support groups**
- 16% need and cannot get access to **home health aides**
- 75% of caregivers say they are more likely now (compared to before restrictions) to:
 - Take better care of themselves (55%)
 - Bring added care support into the home (19%)
 - Ask doctor to change loved one's medication (15%)
 - Ask doctor for medication for their own stress level and anxieties (15%)*(Caregivers could select more than one answer)*
- 72% of those taking care of people with Alzheimer's disease at home were **unsure what would happen to their loved one if the caregiver got sick** with COVID-19
- 43% of caregivers were unsure what to do if their loved one with Alzheimer's became sick
- 74% of caregivers felt **more isolated** than before coronavirus restrictions
- 55% of caregivers were more concerned about their **financial health** and their family's finances than before the coronavirus, a 6-point decline since April
- 32% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**
- 37% said it was hard for them or another family member to be close to a loved one with Alzheimer's 24 hours a day
- 8% of caregivers wanted **government/financial support** such as food stamps or unemployment insurance
- 75% of caregivers said that no additional government/financial support is necessary

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Concerns about Care of Loved Ones in Assisted Living Facilities (36 respondents)

A smaller set of 36 respondents who reported having 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.

- 92% were **unable to see their loved one** because of virus-related visitation restrictions
- 100% supported required COVID-19 testing of all nursing home residents and staff
- Top stressors of caregivers with loved ones in assisted living facilities include:
 - Inability to know/accurately **assess health status** (64%)
 - Concern about facility's ability to adequately care for their loved one (42%)
 - Concern about facility's ability to manage the situation (44%)
- 36% are **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place
- 17% are concerned enough to consider removing their loved one from the facility
- 31% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey (May 8-13), nearly double (14 points higher) than the April survey

Concerns by People Diagnosed with MCI, Alzheimer's or Dementia (52 respondents)

A smaller set of 52 respondents, who identified themselves as having been diagnosed with mild cognitive impairment, Alzheimer's or dementia, reported having higher stress levels, but not as high as caregivers.

- 65% had somewhat or significantly more stress than they did before coronavirus restrictions went into place
- 60% of respondents consistently felt more isolated since coronavirus restrictions were put into place
- 46% of this group said that they were concerned about the health of their loved ones in general, and 27% had specific concerns about the health of their care partner
- Over a third (37%) had concerns about their own health, since the coronavirus restrictions were put into place
- 42% of respondents with a diagnosis believed that their care partner's stress level was higher as a result of the coronavirus outbreak
- Survey comments show increased anxiety and loneliness among diagnosed individuals

General (650 respondents)

Of the total sample, which included those with a diagnosis or at risk for Alzheimer's or another dementia, current and former caregivers, and those interested in brain health:

- 17% 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 dementia 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
 - 5% had to take forced unpaid time off
 - 4% were laid off
 - 1% were required to take vacation
- 64% of women vs 45% of men expressed concern about their financial health.

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Survey Methodology: The survey, taken May 8-13, 2020 by the UsAgainstAlzheimer's A-LIST®, had 650 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, 640 described their status. Current caregivers were the largest group with 176 responses, with a subset of 36 respondents who 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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