

UsAgainstAlzheimer's

UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for July 2020 Survey (Survey #5)

UsAgainstAlzheimer's fielded its fifth survey on the effects of COVID-19 on people affected by Alzheimer's disease and other dementias from July 16-21, 2020. A summary of findings follows.

Declines Seen in Patient Memory and Behavior During COVID-19 Closures and Isolation

- Since coronavirus restrictions, closures, and isolation have been in place, two thirds (67%) of caregivers observed a **decline in their loved ones' memory or behaviors**. This includes 23% who reported a significant decline. Another 28% of caregivers said there had been no change in the memory or behaviors in their loved one.
- More than four in 10 of the survey's patient respondents also said their cognition had declined. Of the 40 patient respondents— those diagnosed with mild cognitive impairment, Alzheimer's or dementia – 58% said there had been no change, 40% said they believe their cognition has declined somewhat; and another 2.5% said they had experienced significant declines.

Significant Effects on Current Caregivers (167 respondents)

- 63% percent of caregivers say their **stress** level is higher since coronavirus restrictions were put in place. This continues a decline over time from a high of 92% in April.
- 83% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress**
 - 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:
 - Sleep problems (38%)
 - Loss of interest in activities (37%)
 - Vigilance/being 'super alert' (36%)
 - Difficulty concentrating (31%)
 - Trouble experiencing positive feelings (29%)
 - Irritable/angry behavior (27%)
- More than a quarter (27%) 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**, down 4 percentage points from the June survey, but up 2 percentage points from the May survey
- 55% of caregivers say their loved ones have experienced a postponement of an annual medical appointment/visit due to coronavirus restrictions; 62% of caregivers indicate that they have postponed their own annual healthcare appointments/visits for these reasons
- 30% of caregivers say they need and cannot get access to **support groups** (up 2 points from June); 17% need and cannot get access to **home health aides**
- 76% of caregivers say they are more likely now (compared to before restrictions) to:
 - Take better care of themselves (52%)
 - Bring added care support into the home (30%) – up 3-points since June and 11-points since May
 - Ask doctor to change loved one's medication (17%)
 - Ask doctor for medication for their own stress level and anxieties (21%)
(Caregivers could select more than one answer)

- 73% of caregivers felt **more isolated** than before coronavirus restrictions
- 53% of caregivers were more concerned about their **financial health** and their family's finances than before the coronavirus
- 22% of caregivers with loved ones at home were **taking their loved one to adult day services prior to the coronavirus restrictions.**
 - Over half those caregivers formerly utilizing adult day services for their loved ones would require staff to wear personal protective equipment (PPE) (58%), require temperature checks of staff before each shift (56%), require routine testing of staff (55%) and require staff to receive special training that follows CDC guidelines (55%) in order to feel comfortable enough to utilize them now.
- 27% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**; 36% said it was hard for them or another family member to be close to a loved one with Alzheimer's 24 hours a day
- 39% of caregivers note that they have less family support for caregiving as a result of coronavirus restrictions

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

- 58% 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. This is lower than previous surveys – which averaged above 70% – but show ongoing uncertainty.
- Nearly three in 10 (28%) said they had nothing in place for the loved one's care in the event the caregiver became sick with the virus. 51% had talked about plans with family or friends, and 21% said they had a written plan, either informal or notarized.
- 35% of caregivers were unsure what to do if their loved one with Alzheimer's became sick
- Caregivers said they have the following measures in place in the event that their loved one becomes sick: Insurance, Medicaid or Medicare (89%); supplies such as gloves, masks, face shields (69%); easily accessed emergency contact numbers (53%); isolation area including toilet (42%); and extra medication and dosing (35%)
 - Written personal preferences – in the event the person living with the disease must to the doctor/hospital alone – were unavailable 89% of the time
- About 16% of caregivers don't have any legal documents in place for themselves; 66% have last will and testament; 62% have living wills/physician orders; 62% have healthcare power of attorneys; 52% have durable power of attorneys; and 31% have HIPAA waivers. Note: This sample is predominantly age 50 & older, with many respondents retired and already having considered end of life planning.

Concerns about Care of Loved Ones in Assisted Living Facilities (31 respondents)

A set of 31 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. The July survey shows 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 lived.

- 68% were **unable to see their loved one** because of virus-related visitation restrictions, a decline of 23 points from the June survey)
- 58% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey (July 16-21), up 8-points since the June survey, 27-points since the May survey, and 41 points higher than the April survey

- Nearly three-quarters of caregivers (71%) said that their **loved one has been tested for COVID-19** (up from 47% in June); 19% said their loved one had not been tested, and one in ten (10%) didn't know
- Over three-quarters (77%) noted that their stress level is worse now as it relates to care of their loved one in an assisted living facility (up 9-points from the June survey)
- 94% supported **required COVID-19 testing** of all nursing home residents and staff, with the remainder unsure or having no opinion (similar to June survey)
- 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 (42%)
 - Communications from facility on status of resources and supplies (39%)
- 36% are **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place, down 8-points from the June survey and similar to the May survey
- 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 (90%), getting tested for Covid-19 before visiting (65%), video visiting as an alternative to in-person visiting (58%), paying for covid-19 testing before visiting (32%).

Unmet Needs of People Diagnosed with MCI, Alzheimer's or Dementia (40 respondents)

A set of 40 respondents, who identified themselves as having been diagnosed with mild cognitive impairment, Alzheimer's or dementia, reported unmet needs during the restrictions.

- 45% of diagnosed individuals want and cannot get services in light of the COVID-19 restrictions. These include counseling (10%), pastoral care / religious services (10%), assistance with food shopping (10%), family support (10%) and a host of other services.

Survey Methodology: The survey, taken July 16-21, 2020 by the UsAgainstAlzheimer's A-LIST®, had 739 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, 667 described their status. Current caregivers were the largest group with 167 responses. Of the 166 caregivers completing the survey, a subset of 31 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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