

Summary of Findings: UsAgainstAlzheimer's Survey on Early Diagnosis and Attitudes Toward Use of a Disease-Modifying Alzheimer's Therapy August 24, 2021

UsAgainstAlzheimer's fielded a survey July 16-August 4, 2021, with responses from 923 people who were diagnosed with Mild Cognitive Impairment (MCI)/Alzheimer's disease (AD) or another dementia, 'at risk' for diagnosis, current/former caregivers and people interested in brain health

Key overall findings include:

- A strong majority (82.6%) of respondents thought early diagnosis was important, and 31.7% said it is even more important in the past year to leverage early intervention / manage care and prepare financially and legally in the face of the COVID-19 pandemic.
- 37.2% of the group who consider themselves to be 'at risk' for MCI/AD or another dementia were more likely to consider diagnosis with the existence of an approved drug treatment that appears to slow – but not stop – the worsening of the disease.
- More than four in five of diagnosed individuals (85.7%) and current caregivers (82.5%) consider it to be important to have access to a treatment that is approved by the FDA and would provide an additional year without worsening symptoms, but with side effects.
- 82.9% of those diagnosed and 80.5% of current caregivers believe that FDA should factor in their willingness to take a treatment before efficacy is fully studied.
- 74.2% of diagnosed individuals and 90.3% of current caregivers were aware of FDA approval in 2021 of a new drug to treat early Alzheimer's disease.

Importance of early diagnosis

- 82.6% of respondents said diagnosis early in the disease course was very important and only 5.1% thought it was unimportant or were unsure. This was relatively consistent across respondent groups, as early diagnosis was seen as very important by:
 - 87.1% of those with a diagnosis
 - 83.6% of those who defined as 'at risk'
 - 81.2% of current caregivers
 - 84.9% of former caregivers
 - 87.1% of those interested in brain health
- Nearly a third (31.7%) of survey respondents now think early diagnosis is more important than a year ago. Another 61.3% of respondents have not changed their opinion about the importance of early diagnosis for MCI/AD in the past year. Those thinking early diagnosis is more important now than a year ago included:
 - 32.86% of those with a diagnosis
 - 27.49% of those defined as 'at risk'
 - 33.8% of current caregivers
 - 28.3% of former caregivers
 - 35.4% of those interested in brain health
- Reasons that early detection is more important now than a year ago included the ability to leverage early intervention to more effectively manage potential disease progression and general well-being (in some cases because they are newly facing a diagnosis), and a change in mindset related to preparation of financial and legal affairs due to the COVID-19 pandemic.

- All respondents except those with a diagnosis of MCI/AD reported willingness to find out if they have AD/MCI at '8' on a scale of 1-10 (1=totally unwilling, 10=very willing), a key reason being enhanced ability for them / their family to better plan.
- 34.1% of the group without a current diagnosis reported that the existence of an approved drug treatment (that appears to slow – but not stop – the worsening of the disease) would affect their willingness to find out if they have MCI/AD.
 - 37.2% of the 'at-risk' group were more likely to consider diagnosis in this situation

Importance of access to treatment / early intervention

- 85.7% of diagnosed individuals considered it important to have access to a treatment that is approved by the Food and Drug Administration (FDA) that would allow them to experience an additional year without worsening symptoms, but with the understanding that there is a chance of side effects.
 - A modification of this question (with assumed future approval) was asked in an earlier survey, January 15-19, 2021; at that time, 78% of those with a diagnosis considered it important to have access to the hypothetical treatment
- In this later survey, 82.5% of current caregivers also considered it important to have access to the described treatment.
- 82.9% of survey respondents with a diagnosis believe that the FDA should factor in the willingness of those with a diagnosis to take the treatment before efficacy is fully studied. 80.5% of current caregivers believe that willingness of those with a diagnosis should be considered.
 - This compares to 84% of those with a diagnosis and 85% of current caregivers who were surveyed on this question in January 2021, before any FDA decision on a treatment

Awareness of a new drug launch in 2021

- Overall, 82.6% of respondents were aware of a new drug that the FDA approved to treat early Alzheimer's disease in 2021. Three in four (74.2%) of diagnosed individuals and 90.3% of current caregivers were aware of the new treatment availability.

Respondents who are not yet diagnosed with Alzheimer's (i.e., at risk, caregivers, interested in brain health) are heavily engaging in brain health to ward off declines; however, about a quarter of them don't think it is possible to prevent

- 48.9% categorized themselves as excited about the possibility to maintain/improve their brain health; 24.6% are worried about brain health decline but knew how to prevent/delay decline; 25.2% are worried about brain health decline but don't think they can do anything about it; 1.7% never think about brain health
- Many individuals cited a variety of options they would consider if they thought they were developing memory problems including: learning strategies/techniques to keep brain fit (89.2%), seeing a doctor (82.2%), participating in a clinical trial (79.2%), and taking Medicare cognitive testing (71.8%)

Survey Methodology: The survey, taken July 16 – August 4, 2021 by the UsAgainstAlzheimer's A-LIST®, had 923 responses. Of the total respondents, 860 described their status: 70 diagnosed with MCI/AD, 154 current caregivers, 198 former caregivers, 291 people who identify as 'at risk,' and 147 people with general interest in brain health. About 9.5%

of respondents were non-Caucasian. This research is overseen by the Advarra Institutional Review Board.

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