

## CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. Our personal insights and preferences are turned into data and validate the collective experience of living with this disease and caring for a loved one. We call it the "science of us."



## The Pulse of the Community

### What Matters Most

The mission of the A-LIST is to use survey results to make life better for the broader Alzheimer's and dementia community. UsAgainstAlzheimer's makes sure that policymakers, researchers, healthcare providers, drug developers, insurers and others who serve this community understand and consider your insights about the Alzheimer's journey when making decisions that affect those living with the disease and caregivers.

### Survey: Brain Health and What Matters Most

Emerging research shows that taking care of brain health as part of overall health can slow the rate of cognitive decline as people age and reduce the risk of developing dementia. This is a crucial part of national efforts to reduce the number of Americans who develop Alzheimer's and related dementias. New research from UsAgainstAlzheimer's A-LIST® finds that while most people think it's important to take care of their brain health, they do not feel informed about the best way to do that. [Read the full A-LIST survey results here.](#)

The 1,435 survey respondents identified themselves as either current or former caregivers, people who consider themselves 'at risk' for developing dementia, people interested in brain health, or individuals diagnosed with Mild Cognitive Impairment (MCI), Alzheimer's disease (AD) or another dementia.

Fully 81% of respondents said they are taking steps that contribute to brain health. In particular, respondents who identified as "interested in brain health" reported engaging in multiple activities to manage brain health. Several activities were not done as often by people with a diagnosis including reading, eating a healthy diet, and maintaining healthy body weight.

**99%**

of respondents said it's important to take care of brain health.

**23%**

of respondents saw themselves as very knowledgeable about brain health.

## KEY ACTIVITIES TO TAKE CARE OF BRAIN HEALTH:

84%	Reading
80%	Exercising
71%	Getting enough sleep
69%	Eating a brain healthy diet
66%	Maintaining a healthy body weight
66%	Socializing regularly
56%	Doing puzzles
54%	Managing health conditions
53%	Managing stress
51%	Playing brain games

### Obstacles

But respondents cited a number of obstacles to taking care of their brain health. More than a quarter (28%) of all respondents were unsure what works and what is a gimmick; others said they're too overwhelmed with other things (24%), too tired (18%), and no time/too busy (16%). About one of four (27%) respondents cited no obstacles to caring for brain health.

"Many people think that time is an obstacle, but the good news is that better brain health does not require adding something to your day, like going to a gym does," said Sandra Bond Chapman, PhD, Distinguished Professor and Chief Director at the [Center for BrainHealth®](#) at the University of Texas at Dallas. "It is about being more strategic with your brain's energy with your everyday mental tasks and stopping habits that are toxic to it. The astounding truth is that brain healthy practices lead to greater efficiency and productivity, which in turn gives you time back in your day and improves your quality of life."



**84%**

of respondents reported not smoking.



**79%**

of respondents reported moderated alcohol use.

When it comes to getting brain health information, respondents said they relied on news articles (69%), internet searches (63%), and healthcare providers (47%).

### Need for National Prevention Goal

Of those who talked to their healthcare providers about brain health, just 26% received relevant information to take home. Respondents who did speak with a physician were more often those with a diagnosis or caregivers. Those respondents who did not consult a physician about brain health said neither they nor their physician thought to bring up the topic during their visits. And only half of all survey respondents felt extremely confident raising the topic of memory or brain health with their healthcare provider.

"The public is hungry to be educated in this area, but people are struggling to find resources and information that could lead to better long-term brain health and possibly Alzheimer's prevention," said Kelly O'Brien, Executive Director of UsAgainstAlzheimer's Brain Health Partnership. "This must change. Doctors, nurses and other providers must regularly discuss brain health with patients, and a national goal to prevent Alzheimer's must be set."

The federal Advisory Council on Alzheimer's Research, Care, and Services recently recommended that the National Alzheimer's Plan be updated to include a focus on risk reduction, and accelerate efforts to reduce risk and intervene early in clinical care. Together

**42%** of current caregivers sought information from caregiver support groups.

**16%** of diagnosed individuals and **12%** of current caregivers sought information from patient support groups.

Diagnosed individuals read less news for information (**39%**) than other

with nearly 200 other organizations and experts, [UsAgainstAlzheimer's is calling on U.S. Department of Health and Human Services Secretary Xavier Becerra](#) to adopt the Council's recommendation.

## Brain Health Bootcamp

Results of this A-LIST research were announced at UsAgainstAlzheimer's National Summit in October as part of the panel, Brain Health Bootcamp. [Click here to listen to the discussion](#) with Dr. Sandra Bond Chapman, Founder and Chief Director, Center for BrainHealth; Dr. Magali Haas, CEO and President, Cohen Veterans Bioscience; Dr. Dean Sherzai and Dr. Ayesha Sherzai, Co-Directors, Alzheimer's Prevention Program, Loma Linda University; and Andres Martin, who is living with the Alzheimer's gene.

## Survey Methodology

The survey, taken September 17-27, 2021, by the UsAgainstAlzheimer's A-LIST®, had 1,435 responses overall from people living with Alzheimer's or another dementia (n=93), current and former caregivers (n=217/262), people with a significant likelihood of developing the disease (n=458), and those interested in brain health (n=405). This research is overseen by an Institutional Review Board (IRB.)

## Survey: Importance of Early Diagnosis

For anyone worried about their own memory, or who has a family member with mild cognitive impairment (MCI), Alzheimer's or a related dementia, deciding whether to seek a definitive diagnosis is a complex issue.

A survey of the UsAgainstAlzheimer's A-LIST® showed nearly 90% of the wider Alzheimer's and dementia community see the importance of early diagnosis of Alzheimer's disease and related dementias. [Read the full survey results here.](#)

- **83%** of respondents viewed early diagnosis as very important
- **7%** viewed it as moderately important

## Advice from Brain Health Bootcamp

- **Define brain health beyond preventing Alzheimer's;** better brain health is better overall health and thriving with the capacities you have.
- **Figure out what you enjoy.** Create connection and purpose.
- **Talk to your doctor** about your risk factors.
- **Understand the choices you make about nutrition,** which makes a huge difference; eat a healthy, clean diet.
- **Be happy.** Find something or someone more important than you.
- **Reset** your mind every morning.
- **Participate in scientific research** so we can learn more and do better.

Nearly a third of the respondents (31.7%) think early diagnosis has become more important in the past year because it allows more time for intervention, more effective management of disease progression, and a chance to prepare financial and legal affairs.

The survey found that 37% of the respondents who believe they are at risk of developing Alzheimer's or another dementia said their willingness to find out their diagnosis would be affected by the existence of an approved drug that would slow the worsening of the disease.

"Families and healthcare providers can use these results as conversation topics to promote brain health, reduce the negative stigma toward dementia, and encourage early detection screenings," says Fayron Epps, PhD, RN, Assistant Professor of Nursing, Emory University. "These results also highlight that everyone has a voice and should be included in treatment and policy discussions."

But the feeling that getting a diagnosis doesn't matter persists, as 25.2% of the survey respondents who are at risk, interested in brain health or caregivers, say they are worried about their brain health – but don't think they can do anything about it. Nearly half of this



**“(Early diagnosis allows for time to prepare, (get) legal forms in order (like power of attorney), make end of life decisions and future care decisions (choose assisted living). Take family photos. Create memories for family to hold (go on a few more family trips). Improve diet and increase mental stimulation early on in case this may help slow progression.”**

– A-LIST Caregiver

group (49%) categorized themselves as excited about the possibility to maintain or improve their brain health; another 24.6% are worried about brain health decline but know how to prevent or delay decline.

Other key findings include:

- **82.6%** of the survey respondents said they were aware of a new drug treatment for early Alzheimer’s that had been approved by the FDA. The agency’s approval of Aduhelm in early June has received widespread coverage, including concerns about the drug’s **\$56,000** annual list price, its effectiveness and the regulatory review process.
- **85.7%** of those diagnosed with Alzheimer’s or MCI considered it important to have access to a treatment that is approved by the 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.

## **CHANGE Act Needed to Encourage More Screenings**

The new survey findings reinforce the importance of passage of the CHANGE Act, bipartisan legislation introduced in Congress to promote earlier detection and diagnosis of Alzheimer’s disease by healthcare providers during the Annual Wellness Visit by patients covered by Medicare.

With someone in the United States developing Alzheimer’s every minute, UsAgainstAlzheimer’s and a range of other groups strongly support the CHANGE Act because more than 60% of Alzheimer’s cases in adults over 65 years old go unrecognized.

To follow up, the A-LIST recently partnered on a second study focused on one-on-one interviews with caregivers to better understand this difficult symptom.

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

## **Thank You**

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