

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

UsAgainstAlzheimer's A-LIST® is an online community of more than 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. A-LIST surveys gather data and personal insights to better understand and share 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 data to make life better for the Alzheimer's and dementia community. UsAgainstAlzheimer's shares anonymous findings with policymakers, researchers, healthcare providers, public health officials, drug developers, insurers and others who serve this community to ensure they consider these insights when making decisions affecting people living with the disease and their caregivers.

A-LIST contributed to the Brain Health Academy by fielding surveys on each of these risk factors to help healthcare providers better understand patient perspectives and needs.

Overall, the results show an awareness about the importance of reducing these risks for developing dementia. However, survey participants said they want more information but are often unsure where to find it. And they want their healthcare providers to talk with them about brain health and managing these risks.

Below are some of the top findings. Read the complete survey results [here](#).

Brain Health Academy



In 2022, UsAgainstAlzheimer's launched the [Brain Health Academy](#) to equip healthcare and wellness providers with the knowledge and resources to help people reduce the risk of developing Alzheimer's or related dementias.

There is scientific evidence that many of the lifestyle habits that are good for healthy aging such as good nutrition, quality sleep, social connection, physical activity and healthy blood pressure, can also reduce the risk of dementia.

Understanding Alzheimer's and Dementia

The introductory Brain Health Academy course provided an overview of Alzheimer's and dementia and the factors behind brain health inequities.

Our A-LIST survey asked about attitudes toward cognitive health and what people want from their healthcare providers to reduce the risk for dementia.

- 69% say cognitive changes during aging is normal
- 90% say Alzheimer's is not a normal part of aging
- 78% say their healthcare provider has not talked with them about ways to reduce dementia risk
- 72% want their healthcare provider to talk with them about risk reduction
- 67% want their healthcare provider to offer a memory screening

Q: If you could ask a healthcare provider a question about brain health, what would you ask them?

- Am I at risk because my mother has Alzheimer's?
- What I can do to prevent cognitive decline, improve alertness?
- Is my brain function normal for my age?

Nutrition

Poor nutrition is a major health problem that affects every part of the body, including the brain. And it is among the top risk factors for dementia. This course provided strategies to assess diet quality and help patients make healthy dietary modifications to build cognitive resilience.

Our A-LIST survey asked about attitudes and challenges related to nutrition.

- 96% believe that nutrition affects the brain and brain health with 71% saying the impact is significant
- Only 14% say their healthcare provider has talked with them about how to eat well for brain health
- Top sources of information on how to eat well: 62% internet, 61% news articles, 28% family/friends, 25% health care providers, 18% social media
- Top factors impacting ability to maintain good nutrition: 64% exercising, 59% education and understanding of nutrition, 57% getting enough sleep, 55% access to nutritious food, 53% moods/feelings, 49% high stress or stressful situations

Sleep

This Brain Health Academy course focused on the connection between sleep and dementia, and strategies to help patients optimize sleep. Our A-LIST survey asked about challenges in getting quality sleep.

- Overall, only 44% believe they get enough sleep and feel well rested
- Statistically significantly - more current caregivers say they do not get enough sleep or feel well rested, as compared to those interested in brain health
- 52% overall worry about getting enough sleep, with current caregivers more likely to worry
- 50% of those with sleep concerns have not spoken with their healthcare provider about their sleep

Top factors impacting ability to get enough sleep

- 59% high stress/stressful situations
- 55% racing thoughts
- 47% moods/feelings
- 44% exercising
- 42% health conditions (i.e. hot flashes, gastric issues)

Social Isolation & Loneliness

During the pandemic, we saw the impact that social isolation and loneliness had on mental health. Studies also show these are risk factors for cognitive decline. This course focused on tools for healthcare providers to assess social activity and loneliness in patients, and strategies to improve mental health and reduce the dementia risk.

Our A-LIST survey asked about feelings of social isolation and how healthcare providers can help.

- 90% of respondents believe feeling socially isolated has some or significant effect on the brain and brain health (+ or -)
- As many as 30% may feel socially isolated
- Of those who feel socially isolated: 67% feel more socially isolated than before the pandemic, and 92% say they are affected emotionally, 81% mentally and 56% physically
- 42% of respondents say they do not socialize as much as they would like to:
 - 54% feel they lack companionship at least some of the time
 - 45% feel left out at least some of the time
 - 45% feel isolated from others at least some of the time
- Social isolation is more prominent in those with a diagnosis of AD/DRD

Q: How can health care providers (HCP) help their patients manage feelings of social isolation and/or loneliness?

- “Educate about the role of social isolation and loneliness in depression and risk of dementia.” (former caregiver)
- “Have a list of community resources available to give to patients – places or events to visit for socialization.” (former caregiver)
- “Encourage them to exercise regularly outdoors.” (former caregiver)
- “Refer for talk therapy.” (ADRD/MCI diagnosis)

Physical Activity

People who are physically active are less likely to experience a decline in their mental function and have a lowered risk of developing dementia. This course provided guidance and tools to help providers address exercise with patients.

Our A-LIST survey asked about levels of exercise, keys to getting enough exercise, and how healthcare providers can help.

- 98% believe that exercise or physical activity affect the brain and brain health
- 60% have spoken with their healthcare provider about their physical activity
- 83% exercise 2X a week or more with 1/3 exercising nearly every day
- Self-motivation is a key motivator to exercise (26%); others include: changes to personal life (28%), more time (22%), workout partner (21%), fitness center location (16%), and better weather (15%)

Q: What do you need from your health care provider in order to improve your physical activity?

- “To ask the question and hold me accountable the next time we meet.”
- “A non-pharmaceutical approach to resolving hip, knee, and leg pain.”
- “Ask me how I keep active, give me a realistic goal and types of physical activity to attain the target goal.”
- “A kick in the pants!”

Hypertension

Managing blood pressure can reduce the risk of cognitive decline and dementia. This Brain Health Academy course provided guidance on the latest science and best practices for community education.

Our A-LIST survey asked about aspects of maintaining blood pressure to avoid hypertension.

- 93% believe that hypertension has some or significant effect on affect the brain and brain health
- 1/3 (33%) have high blood pressure and 6% are unsure
- Strategies used to maintain a healthy brain and body: regular medical checkups (79%), eat a healthy diet (71%), exercise regularly (67%), get a good night's sleep (64%), limit alcohol consumption (63%), maintain a healthy weight (60%), take prescription medication (56%), reduce salt/sodium (51%)
- Smoking: 34% are ex-smokers and 3% are current smokers; fewer caregivers are ex-smokers
- Alcohol intake: average 0 drinks/day (68%), average 1 drink/day (25%), average 2 drinks/day (5%), average 3 or more drinks/day (2%)
- Fried food intake: less than 1X/week (66%), 1-2X/week (28%), 3(+X)/week (6%)
- Daily coffee intake: none (35%), 1-2 servings (50%), 3+ servings (15%)

Thank You

Thank you to our friends at Home Instead Senior Care for their collaboration on fielding the survey on social isolation and loneliness, and sleep.



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