

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The 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 leverage data to make life better for the Alzheimer's and dementia community. UsAgainstAlzheimer's shares our findings with policymakers, researchers, health care 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.

Stigma & Dementia

How we think about Alzheimer's and other dementias has a profound effect on people who are living with the disease and their loved ones. These attitudes, and related stigma, influence every step of the Alzheimer's and dementia journey, including whether they are willing to talk about it, how people with the disease and caregivers feel they are treated, how doctors approach diagnosis, and whether people are even willing to seek information about brain health.

Podcast: BrainStorm

Culture plays a role in stigma for Black Americans as well when it comes to dementia and Alzheimer's, according to Dr. Pernessa Seele. Dr. Seele is founder and CEO of The Balm in Gilead and author of the book, [Stand Up to Stigma: How We Reject Fear and Shame](#). Dr. Seele spoke with UsAgainstAlzheimer's Meryl Comer for the [BrainStorm](#) podcast.



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"People still think about it as an aging issue. Momma, Daddy, Uncle, they're getting old now, and getting a little senile. But you start talking about the interventions and the tools that are now available – sometimes people don't want to go and get access because, well, this is just normal. We have to continue to go into communities, neighborhoods, and churches, and educate and lift up those families." — Dr. Pernessa Seele, Founder and CEO, The Balm In Gilead

Survey: Attitudes toward Dementia

The A-LIST April survey asked how people living with dementia feel about different aspects of Alzheimer's or dementia. We also wanted to understand the perspectives of caregivers and people who are interested in brain health, but who don't have a personal connection to dementia.

The results were presented to public health officials from across the country in June at the [BOLD Center of Excellence for Dementia Caregiving](#) conference. [Read the complete results here.](#)

Living with Dementia

These respondents reported relatively modest stigma mostly related to feeling left out of things, seeing that people are uncomfortable with them, and embarrassment about their illness and physical limitations.

Q: Because of my illness, I feel left out of things:

30%	Never
22%	Rarely
30%	Sometimes
7%	Often
6%	Always
6%	N/A

Q: I feel embarrassed about my illness:

35%	Never
17%	Rarely
30%	Sometimes
11%	Often
6%	Always
2%	N/A

Q: Because of my illness, people are unkind to me:

59%	Never
24%	Rarely
7%	Sometimes
2%	Often
2%	Always
6%	N/A

Caregivers

Caregivers reported more types of stigma than other groups. Many caregivers also observed that the care recipient is treated differently by family, health care providers, and others. Further, they believed that the diagnosis either has or will affect the person with dementia's ability to function as a spouse, parent, or grandparent. And more than half of the respondents (55%) said they feel some guilt.

Q: To what extent do/did you experience a reduction in your social contacts after the diagnosis?

10%	Not at all
12%	Small extent
16%	Some extent
22%	Moderate extent
28%	Always
13%	N/A

Q: To what extent do/did you feel that the person is treated differently by family members since the diagnosis?

9%	Not at all
15%	Small extent
19%	Some extent
19%	Moderate extent
33%	Always
3%	N/A

Q: To what extent do/did you feel guilty about the person's situation?

44%	Not at all
19%	Small extent
15%	Some extent
11%	Moderate extent
10%	Always
1%	N/A

Q: To what extent do/did you think that the diagnosis will/did affect the person functioning as a spouse?

1%	Not at all
1%	Small extent
6%	Some extent
11%	Moderate extent
58%	Always
25%	N/A

Interested in Brain Health or at Risk for Dementia

Survey respondents without a direct connection to someone with dementia reported having positive feelings about people with a dementia diagnosis and working with them. Only 9% of respondents said they were afraid of individuals with dementia. However, 46% would avoid an agitated person. These respondents noted that familiarity with dementia is key but feel somewhat frustrated about knowing how to help them. This group said they admire the coping skills of people with dementia.

Q: It is possible to enjoy interacting with people with dementia.

2%	Strongly disagree
1%	Disagree
1%	Somewhat disagree
4%	Neutral
14%	Somewhat agree
48%	Agree
30%	Strongly agree

Q: We can do a lot now to improve the lives of people with dementia.

2%	Strongly disagree
1%	Disagree
1%	Somewhat disagree
4%	Neutral
14%	Somewhat agree
48%	Agree
30%	Strongly agree

Coming in Fall 2022

Lucidity in Dementia

Sometimes people in the later stages of dementia who have lost the ability to express themselves have lucid moments when they are able to communicate in some way. The A-LIST is collaborating with researchers from the Mayo Clinic's Kern Center for the Science of Healthcare Delivery to learn more about why these lucid moments happen. Our early research shows that episodes of lucidity can have a profound effect on caregivers and may be brought on by a variety of factors.

We want to learn more to help caregivers prepare for and make sense of lucid moments. This will improve their interactions with their loved ones living with dementia and help manage their own emotions. Next year we will be asking current caregivers if they are interested in participating in a year-long study on lucidity. More information to come this fall.

Thank You

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