



The Pulse of the Community

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Today, the A-LIST is part of a broader effort called AD PACE, an UsAgainstAlzheimer's patient and caregiver-led collaboration among industry, government agencies, care providers, and advocates to deliver new insights to researchers, regulators and payers on what patients want most from treatment.

FINDINGS OF "WHAT MATTERS MOST: EARLY DIAGNOSIS"

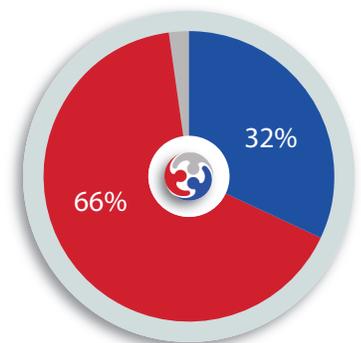
The A-LIST has fielded 12 surveys and received more than 18,000 responses. The latest survey, fielded in partnership with Quest Diagnostics, asked people in the A-LIST about their opinions and experiences with cognitive assessments. The bottom line? A large majority of people would like to get information about cognitive assessments from a medical provider, but two-thirds say that conversation has not taken place.

Some of the key findings:

- Approximately two-thirds (66%) of A-LIST respondents have not discussed early cognitive assessment with a medical provider.

HAVE YOU HAD A DISCUSSION WITH YOUR MEDICAL PROVIDER ABOUT EARLY ASSESSMENT OF COGNITIVE IMPAIRMENT?

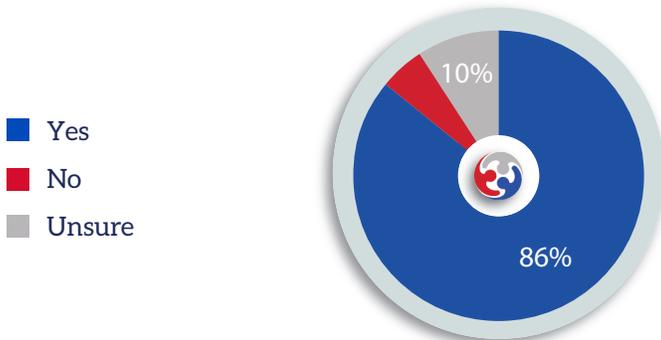
- Yes
- No
- I don't have a medical provider



- Two-thirds (67%) of respondents said they were somewhat or slightly knowledgeable about the benefits of early cognitive assessment. Only 24% were very or highly knowledgeable.
- Respondents said they prefer to get information about cognitive assessment testing from providers in the medical community (78%) or from trustworthy online sources (65%). Only 17% said they wanted that information from family, friends or acquaintances.

- People who responded were very receptive to using an online screening tool. 86% said they would be willing to use such a tool to get an immediate assessment and 87% said they would share findings from an online cognitive assessment tool with their doctor.

WOULD YOU BE WILLING TO TAKE A COGNITION SELF-ASSESSMENT TOOL ONLINE?



Early diagnosis is essential to getting people effective care and offers researchers an opportunity to better understand the progression of the disease. One of the keys to curing Alzheimer’s is getting enough people in the early stages of the disease into clinical trials. That’s how we’re going to find out which treatments are most effective at slowing, stopping, or preventing the disease.

One thing people can do to support early detection is to advocate for passage of the CHANGE Act, which facilitates earlier identification and treatment of Alzheimer’s, encourages innovative approaches to support family caregivers, and removes regulatory barriers to effective treatments. Without the provisions set forth in the CHANGE Act, people are likely to continue to be diagnosed in the late stages of the disease, when there is little hope of stalling or reversing its impact.

VOICES FROM THE A-LIST

Why Would You Share Findings from a Cognitive Self-Assessment with Your Doctor?

“So he would have a baseline to monitor me. My mother suffered from Alzheimer’s, so I have a fear of getting it.”

“I would like to find out about anything that can be done to help as early as possible.”

“It’s a good baseline to see if there would be any deviation over time and to plan for future.”

“To be referred to a neurologist and possibly begin treatment.”

BRIAN VAN BUREN

Advocacy has long been an important part of Brian Van Buren’s life. He was an AIDS/HIV activist in the 1980s and 1990s after two of his partners died of AIDS. He eventually coordinated Ryan White HIV/AIDS Program funding in California. Now 67 years old, Brian lives in Charlotte, NC. He was diagnosed with Alzheimer’s in 2015.

Brian is at least the third generation of his family to have the disease. Both of his grandmothers had Alzheimer’s, as did his aunt and his mother, who died of it in January 2018. Brian was the primary caregiver for his mom for the last ten years. He estimates he spent about \$400,000 on her care before she eventually was eligible for Medicaid. At the same time, Brian was working full-time as an international flight attendant. He first noticed something was wrong when he had trouble remembering the in-flight safety instructions, even though he had been saying them for 20 years. More than once, he welcomed a planeload of passengers to New York’s JFK airport, when they had actually arrived in Washington, DC.

Brian's diagnosis came at a time when he faced a lot of health issues, some possibly tied to the stress of managing his career and caring for his mom, in addition to having trouble with his memory. Brian says he was overweight, and had high blood pressure, high cholesterol, type 2 diabetes, and sleep apnea. On a flight from the U.S. to Brazil in February 2015, Brian had a heart attack. The plane made an emergency landing and he spent two weeks at a hospital in Puerto Rico. When Brian got back to the mainland for treatment, he met with a psychologist who ordered an MRI and then gave a diagnosis of vascular dementia. "People tell me I don't look like I have Alzheimer's," says Brian. "They expect someone older. But you can get early-onset Alzheimer's when you're fifty." In the last few years, Brian has improved his overall health despite having Alzheimer's. "I've totally turned my health around," says Brian. "I lost 25 pounds, my blood pressure and cholesterol have dropped, and I sleep soundly with a C-PAP machine."



Brian's passion as an Alzheimer's advocate is working with the African American community. "Our risk is twice the overall population's, but I go to many conferences and I see only a few black faces."

"We need more discussion with doctors about our mental status, throughout our lives," says Brian. "Too often, they rush past that."

Brian gets a lot of spiritual, emotional and practical support from people at his church. "As soon as I started going to this church, I made an announcement that I have Alzheimer's. It turns out five other people at the church do, too. People at the church are very supportive—they take me to medical appointments, and they visit me at home."

"A few months ago, I went to church and I had my clothes on backwards. Everyone there knows I have Alzheimer's, so they helped me out."

"I would like to see more information about Alzheimer's in the African American churches around Charlotte," says Brian. "Black people are still suspicious of health care because of things like the Tuskegee study. Also, many people just don't have access to health care."

“Our risk is twice the overall population's, but I go to many conferences and I see only a few black faces.”

Brian has developed some coping strategies. As soon as he gets in his car, he enters his destination in his GPS, even if it is nearby, so he doesn't get lost or forget where he's going. He also keeps his keys and phone in a specific place in his home. "That way I don't find them in the refrigerator, or the trash," he says.

Brian is worried about the future, and how he will be cared for. He is a veteran of the U.S. Navy and looking into care from the U.S. Department of Veterans Affairs. Brian was married two years ago, but he says the relationship broke up because of the strain from living with Alzheimer's. Brian thinks he might have been diagnosed sooner if he had been living with someone. He suspects he started to have symptoms ten years before he was diagnosed. Living alone also presents problems now, because he doesn't have a live-in caregiver.

Brian supports the CHANGE Act as a way to better support in-home caregivers. "Most of the caregivers I know live in the home," he says. "It's very stressful to be in that environment 24/7."

GABY AND MATT GANDAL

Gaby Gandal, 84, has always been very independent. She built and ran a successful real estate company in Chevy Chase, MD, while raising two boys and being a leader in the community. “My brother and I are very proud of her and her accomplishments,” says her son and primary caregiver, Matt, who lives nearby.

A few years ago, her sons noticed their mom was repeating herself and having trouble operating a computer that she had used for years. “She had always been very detail oriented, but then she started losing track of things around the house,” says Matt. “She wasn’t neat and tidy anymore.”

When a doctor told Gaby - and her sons - that she was in the early stages of Alzheimer’s, she resisted the diagnosis. “She didn’t want to be labeled as having Alzheimer’s,” says Matt. “She said she was just getting older, that she’d always had memory problems.”

Eventually, Gaby fell and broke her hip. She had surgery and spent time in a rehabilitation center. “That’s when we realized how deep her challenges were,” Matt says. “She would wake up and try to get up, not realizing where she was or that she had just undergone surgery.” When Gaby returned home, Matt arranged for her to get nearly full-time at-home care.

She still loves being in her house. “What makes my mom so happy - even today - is staying in her own home. Why rob her of that?”

👍👍 Until we get a cure, the best way to make things better now is to make it easier for caregivers so we can improve patients’ quality of life. Allowing reimbursement for in-home care would be huge. My family is lucky enough to be able to afford it, but many people can’t. 🗨️🗨️

One of Matt’s challenges as a son and caregiver is figuring out how best to relate to Gaby: “Early on, I tried to correct her when she said something incorrect, but I realized that was not helpful. There’s no easy playbook for caregivers.”

“She’s not as communicative now,” he says. “I’m learning what it means to spend quality time together when you can’t have a back and forth conversation. It’s been a challenge, one that I’m still working on.”



Matt struggles to manage the time commitment and mental burden of being a family caregiver, running his own business, and having a family with kids. He supports putting policies in place to help caregivers and make care more affordable. That’s why he hopes Congress will pass the CHANGE Act. “Until we get a cure, the best way to make things better now is to make it easier for caregivers so we can improve patients’ quality of life,” says Matt. “Allowing reimbursement for in-home care would be huge. My family is lucky enough to be able to afford it, but many people can’t.”

BRADY JOHNSON AND BARBARA SCOTT-JOHNSON

Before he developed Alzheimer's, Brady Johnson, 80, was a former college basketball star, an Army veteran, a retired education administrator, and a provider for his family. "He was a brilliant man, and now I see him struggle with basic tasks," says his wife and caregiver, Barbara Scott-Johnson.

"Even before being diagnosed with Alzheimer's, Brady knew something was wrong, but people go into denial and that's what happened to us. We thought 'this is just what we all go through.'"



Taking care of Brady full time has been a stressful and sometimes overwhelming responsibility. As retirees, "Our lifestyle has changed significantly because of Alzheimer's. Going to a support group has helped me. The staff members and other participants have helped me get over my anger and frustration. Because of Brady's illness, I had to give up or curtail going to my exercise class, Bible study and other everyday activities. However, we now do more things together."

For example, "We're in an exercise program two times a week. It's called Silver Sneakers. This program also assists with focusing on a person's cognitive development, balance and social interaction."

"I began seeing that our journey with Alzheimer's had started to wear me down. I knew I had to get Brady involved in an adult day care program a couple of times a week. This has helped Brady and it has helped me too. I needed time to myself - a break. Scheduling multiple events and activities has been a challenge, but I try to always schedule our Silver Sneakers time because Brady has a lot of friends there and it is relaxing and therapeutic for both of us."

"My saving grace through this all has been my faith. I'm a spiritual person and that helps," says Barbara. "Brady is a greeter at church with me once a month and he's still a very sociable person. I have also encouraged him to stay involved and busy with his fraternity and the American Legion. He still needs these social interactions to keep his mind engaged."

In the past, Barbara has been very frustrated by the lack of information she has received from doctors. One of the reasons Barbara supports the CHANGE Act is that it has provisions to encourage primary caregivers to track brain health: "Doctors need to listen more to the caregivers to get a better idea of the everyday occurrences in patients' minds and interactions."

"Lately, we've been going to a neurologist to seek help with Alzheimer's and she's been great!" says Barbara. "She listens and explains things like the PET scan, which shows the plaque inside of Brady's brain."

“My hope is that we’ll be able to help someone else who is suffering with Alzheimer’s. That’s why I want to talk to so many people about Alzheimer’s because our collective efforts may one day lead to a cure.”

As a caregiver, Barbara has a few strategies to help Brady: "I've created a schedule filled with activities each day that has created a routine for Brady. Each morning he gets up and asks, 'What are we doing today?' I also stage things like Brady's cap,

his iPhone, his meds, and the remote to reduce his frustration. I just want to give him a comfortable but routine daily pattern. Having a routine has helped us tremendously.”

Other caregivers have come to Barbara for advice. “My hope is that we’ll be able to help someone else who is suffering with Alzheimer’s. That’s why I want to talk to so many people about Alzheimer’s because our collective efforts may one day lead to a cure.”

Her advice? “Anger is an initial feeling that the caregiver feels when your loved one does something that’s totally irrational. Anger is a natural feeling that we all feel, but when we learn more and understand the disease more we learn not to get mad at our loved one. Sometimes now I get the biggest laughs from things that my ‘new’ Brady does. You have to continue to live, love and laugh by doing things together.”

ADPACE A-LIST

Patients and families transforming Alzheimer’s research



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