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Their Dementia Diagnosis Doesn't Mean They're Keeping Silent

More people with Alzheimer's and other brain diseases are forming organizations to boost understanding about their conditions on their own terms



Mark Roberts relies on his service dog, Sophie, to fetch his medication and calm him when he is anxious. He was diagnosed with younger-onset dementia in 2014.

PHOTO: NICK KING FOR THE WALL STREET JOURNAL

By
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As the number of people with dementia grows, more of them are speaking out to challenge assumptions about what they can and can't do.

Dementia affects more than 55 million people world-wide, with more than double that number expected to receive a diagnosis of the chronic condition by 2050, [according to the World Health Organization](#). A group of advocates, many in the earlier stages of this condition, say that people around them often struggle with understanding the full range of symptoms.



Brian LeBlanc, a dementia advocate and educator, found out he had younger-onset Alzheimer's in 2014, making him the fourth generation in his family to be diagnosed with dementia.

PHOTO: BRANDI IMAGE PHOTOGRAPHY

They have responded by forming self-advocacy organizations, aiming to shift the focus away from dementia's end stages. Many use a motto speaking to their desire for inclusion: "Nothing about us, without us." Their goal is to help healthcare

professionals, policy makers and family members better understand the complexities and limitations, as well as the possibilities, of living well with dementia. Another priority for them is dispelling the widespread stigma surrounding the brain disorder that includes several types of diseases, including Alzheimer's.

“There is still life after a dementia diagnosis. That is what a lot of people don't understand,” says Brian LeBlanc of Clearwater, Fla. He was diagnosed with younger-onset Alzheimer's in 2014 and [has been an advocate ever since](#). “I'm not sitting in my house withering away.”

The 61-year-old former public relations and marketing executive began giving speeches the year after his diagnosis on behalf of the Alzheimer's Association. [He also writes a blog](#). He helped found the National Council of Dementia Minds.

It was like crashing into a wall. I went from working 60 hours a week to zero.—
Arnold Beresh, 68

That organization grew out of a presentation by eight people with dementia to long-term care providers in 2019. [It now has members in 13 states](#), ranging in age from 46 to 85. All have been diagnosed with dementia—some less than a year ago and others 11 years ago. They offer training and educational series on how dementia affects hearing, smell and taste. They explain how routines, automatic bill paying, electronic notepads and therapy dogs equipped with GPS trackers help them function more independently.

During these sessions, which have reached more than 4,000 people in four countries, they also [talk openly about losing jobs and friends](#) and the worst things people can say to them.

Among them: “You don't look like you have dementia.”

“I forget things, too.”

“Go live your life.”

Bonnie Erickson, 61, recalls hearing those last four words in her doctor's office after learning that she had white matter disease and vascular dementia. She received no informational pamphlets or other follow-up instructions. She searched the internet for answers, unsure of what to make of that advice.



'It's not just a memory issue as so many think it is,' says Bonnie Erickson, who was diagnosed with vascular dementia in 2018.

PHOTO: BONNIE ERICKSON

"What I found frightened the hell out of me," says Ms. Erickson, a former program analyst with the Department of Homeland Security who lives in Billings, Mont. Since then, she has joined [Dementia Alliance International](#), whose governing body also consists of people with dementia, and is president of the National Council of Dementia Minds.

"My personal goal is to improve the diagnosis process from, 'Go get your affairs in order,' to, 'Here are some resources that may help you understand your diagnosis and live well,' " she says.

Stigma often prevents people from seeking a diagnosis. This is a mistake, says Mark Roberts, 69, who was diagnosed with vascular dementia.

You know what? I got a purpose. You know what? I have a life. You know what? I can still do things.

— Theresa Montgomery, 65

A skilled tradesman in Elwell, Mich., who loved trout fishing and gardening, Mr. Roberts grew uncharacteristically agitated and frustrated at work and home soon after he turned 60. He lashed out at his wife, Brenda Roberts, who endured his mounting anger until late 2013, when he threatened to get a gun and “put an end to this” because he couldn’t get a door installed.

“I thought he had just become an angry man,” says Brenda, who had worked with older adults for 40 years but never suspected he had dementia. She went to live with her daughter and insisted he see a neuropsychologist.

After initial counseling sessions, Mr. Roberts saw a geriatric psychiatrist who diagnosed him with vascular dementia at the age of 62. As part of the National Council of Dementia Minds, he gives presentations, often with Brenda, about how obtaining a diagnosis explained his behavior and saved his marriage. Brenda Roberts is executive director, facilitating training and presentations.



Brenda Roberts, whose husband, Mark, has dementia, brought the original founders of the National Council of Dementia together for a long-term care conference in 2019 and is now executive director of the nonprofit.

PHOTO: NICK KING FOR THE WALL STREET JOURNAL

Advocates often describe how they repurposed their lives after losing their jobs.

Arnold Beresh, a 68-year-old podiatrist, had been practicing for 35 years, when he began having problems multitasking and finding his way home. He compensated for a while, bringing people into meetings to take notes for him. A 2015 visit to a specialist confirmed his worst fear: early-onset frontotemporal dementia.

“You are done,” he recalls the doctor saying. “It was like crashing into a wall. I went from working 60 hours a week to zero.”



Arnold Beresh, with his wife, Michele, says people often tell him he doesn't look like he has dementia. 'What is a person that has dementia or Alzheimer's supposed to look like?'

PHOTO: MICHELE BERESH

[He and his wife](#), Michele Beresh, moved from Newport News, Va., to West Bloomfield, Mich., to be closer to family. To help fill the void left by losing his practice, he works with the Michigan Dementia Coalition and National Council of Dementia Minds. He meets with small groups of people and answers questions about living with dementia. "It helps keep some of my world straight, and it gives me a sense of purpose," he says.

Acceptance and adjustment are key, says Theresa Montgomery, 65, of Duluth, Ga. She was 58 when she received her younger-onset Alzheimer's diagnosis. She thought she might be dead within five years.

She says she had a choice—mope or get busy—and she chose the latter, serving as an adviser and speaker for three dementia-related groups. Life expectancy for those with early-onset dementia varies. One 2019 study showed a mean survival time of 17 years after symptoms start and 10 years after a diagnosis.



Theresa Montgomery was 58 when she received an Alzheimer's diagnosis. She wants to raise dementia awareness among younger people.

PHOTO: THERESA MONTGOMERY

"I don't want to have this, but I have to accept it," Ms. Montgomery says. Her short-term memory is getting shorter and she has trouble sleeping. "But I always keep something on my plate," she says. "You know what? I got a purpose. You know what? I have a life. You know what? I can still do things."

Some associate dementia only with memory loss. Many of the advocates also describe other symptoms so family members and healthcare professionals can be aware.

Steven Barbieri, 60, appeared to be hard of hearing. His wife, Tracy Barbieri, asked him to get his ears checked after he didn't pick up their daughters at school as requested. "She thought I had selective hearing," he says.

His hearing was fine, so his doctor referred him to a neurologist, where he went through a series of scans and tests, including drawing a clock. “Mine looked like a 6-year-old drew it,” says Mr. Barbieri, who was 51 at the time. He received his dementia diagnosis and retired two days later from Wells Fargo, where he was district manager in Modesto, Calif.

He learned that with dementia, his brain couldn’t process all the words he heard, so he might miss two out of four words in a conversation. He describes that experience during presentations for the Alzheimer’s Association and National Council of Dementia Minds.

Knowing the importance of exercise and diet, Mr. Barbieri goes to the gym regularly, takes 12 nutritional supplements, [follows a Mediterranean diet](#) and sleeps seven to eight hours a night. He and his wife decided to move to Idaho.

“I do things now,” he says. “I want to die with memories. Not dreams.”

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