The Isolation Alzheimer’s Brings

Many people in the early stages of dementia find themselves isolated, even from those they thought they could count on

By Clare Ansberry, The Wall Street Journal Oct. 26, 2019

When Keith Moreland, 58, was diagnosed in the early stages of Alzheimer’s in 2018, he noticed that friends stopped including him and his wife, Sheri, on outings.

“I would see all these posts about “Had a great time with so and so,” says Mr. Moreland, a former inventory analyst who now works with his wife at their consignment boutique in Anderson, S. C. “We’re never invited to be a part of that anymore. Maybe I don’t remember some stuff, but I’m still Keith.”

Many people diagnosed with dementia experience the same feelings of being left out. A recent global survey by Alzheimer’s Disease International found that 38% of those living with dementia in high-income countries, including the U.S., report feeling avoided, ignored and ostracized in their social lives.

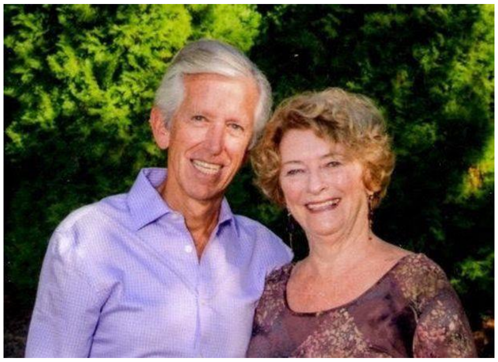
“I call it the friendship divorce. I have lost a fair amount of people in my life that I at one time considered friends,” wrote one respondent, while another said, “People tend to run when they learn you have dementia.”

Mr. Moreland, a former inventory analyst, now works with his wife, Sheri, at their consignment boutique in Anderson, S.C.
PHOTO: DANIELLE PAUL FOR THE WALL STREET JOURNAL

Such reactions partly reflect a lack of understanding of the many stages and types of dementia, which affects nearly 50 million people globally and is expected to almost triple by 2050, according to the World Dementia Council. Those in the early and mid-stages, which can last for years, continue to work, volunteer and travel, says Monica Moreno, senior director of care and support at the Alzheimer's Association.

"It's part of who they are, but doesn't have to define them," she says. On average, a person with Alzheimer's disease, one of the most common types of dementia, lives four to eight years after diagnosis, but can live as long as 20 years, according to the Alzheimer's Association.

Yet the stereotype persists that everyone with dementia is old, feeble and acts strangely, says Geri Taylor, 76, who was diagnosed with a mild cognitive impairment in 2012, and subsequently Alzheimer's.



Some people are afraid of what a dementia patient might do, says Geri Taylor, diagnosed with Alzheimer's, here with her husband Jim.
PHOTO: VAN DEMAN PHOTOGRAPHY

"Those who define themselves by doing things the right way and being courteous and neat are afraid that people with Alzheimer's might show badly," says Ms. Taylor, who lives in New York City and worked 45 years in the long-term care industry. Her own friends, she says, have remained close, a group of them often lunching together, which her husband, Jim, credits in part to Geri's efforts to call and reach out to others.

The friendship divorce goes both ways, says Greg O'Brien, a 69-year-old journalist who was diagnosed with early-onset Alzheimer's about nine years ago and lives on Cape Cod. He's lost friends, who he says slip away because they are afraid and don't know what to say. He has also walked away from some.

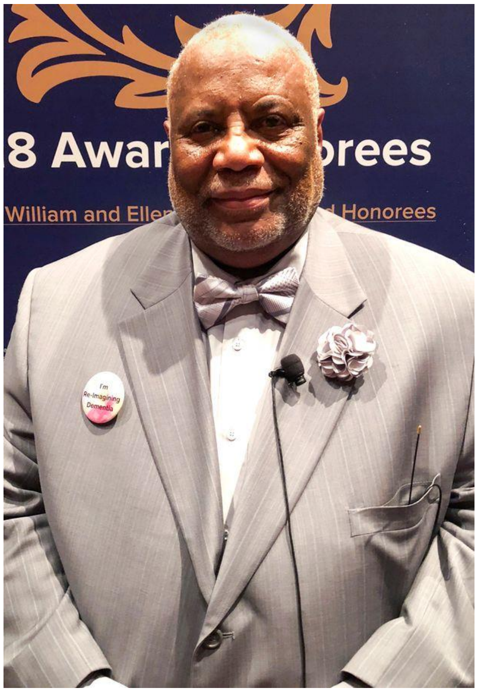
"I don't spend time with people who don't seem to understand the journey. I don't judge them or hate them. I just stay away from them," says Mr. O'Brien, author of the 2014 book "On Pluto: Inside the Mind of Alzheimer's."

His close friends circle the wagons around him, he says. They approach him, hug him, say "Hi, Greg. It's Jim." If he seems withdrawn at a gathering where the noise and conversation are overwhelming, they touch his shoulder or hand to let him know they are there. "A simple hug or touch is so important in Alzheimer's," says Mr. O'Brien, who is on the board of USAgainstAlzheimer's, an advocacy and research organization. "We're not lepers."

'I don't spend time with people who don't seem to understand the journey,' says Greg O'Brien, who found he had early-onset Alzheimer's nine years ago. PHOTO: AMY DYKENS

Brian Van Buren, in the early stages of dementia, knows how a lack of understanding can affect a relationship. After being diagnosed about four years ago, the 68-year-old former flight attendant in Charlotte, N.C., broke up with his partner, who grew frustrated at his forgetfulness.

"I would ask him a question, sometimes five or six times, and he would yell at me, saying, 'You asked that already. You're not paying attention,' " says Mr. Van Buren. "I didn't need that kind of stress in my life." They separated for a year and are now back together. His partner has a better understanding of the disease and accompanies Mr. Van Buren, who is on the advisory board of Dementia Action Alliance, to conferences.



Brian Van Buren, in the early stages of dementia, for a time separated from his partner, who showed frustration at his forgetfulness.
PHOTO: BRIAN VAN BUREN

In South Carolina, the Morelands wanted friends to know about Keith's diagnosis and began telling them, starting with their church, which was a big part of their lives and where he played the bass guitar.

Mr. Moreland made the announcement after services, while everyone was still in their pews. He wasn't sure how his fellow churchgoers would react. "People stared and went the other way," he says. The pastor avoided the subject. Eventually the couple changed churches.

The reception wasn't much better when he mentioned his diagnosis on Facebook. Of his 200 Facebook friends, seven responded.

"There's a lot of stigma around Alzheimer's. People don't know what to say or do," Mr. Moreland says. Some have said, "Don't worry. I forget things, too," which to him is like telling a cancer patient, "Don't worry. I get sick, too."

"They don't get it," says his wife, Sheri. "He doesn't just forget things. There are times he doesn't know where he is or how he got there."

Mr. Moreland continued working as an inventory analyst for nine months after his diagnosis, before going on disability in March. Now he helps Sheri at Ladies on Main, their consignment boutique and her long-time dream, which they had bought just before his diagnosis. He handles online sales and social media and fixes the computer when it freezes.

Customers sometimes whisper "How is Keith?" when he is sitting nearby. "He's right here. Why don't you ask Keith how Keith is doing? He can say if he's fine or having a bad day," she responds.

People are friendly in the store and at their new church. But few invite them to their homes or for dinner. "I think people are scared of more intimate settings, being one-on-one with me," he says.

A few times a month, they gather with others who have early-onset Alzheimer's, a plumber, a dentist, a crane operator, a university professor and their spouses. They play cards and board games. With them, Mr. Moreland says he doesn't worry about forgetting what he was going to say or whether his last sentence made sense.

"Truthfully, most of my close friends from before the diagnosis are gone," he says. "I have one who hung with me on both sides. That's about it."

'I want all the information I can get so I understand,' says Nancy Blanchard, who has remained a close friend to Mr. Moreland. PHOTO: KATHY SMITH IMAGES

That one person is Nancy Blanchard, who lives across the street from their downtown boutique in a renovated hotel. When they told her about Keith's diagnosis, she asked questions about the diagnosis, how they were handling it and what she could do.

"I'm an old-school teacher and never thought any question was out of bounds. I want all the information I can get so I understand," she says.

That is refreshing, says Mr. Moreland, who is on an early-stage advisory group for the Alzheimer's Association and working to reduce stigma. He is meeting with local business and civic leaders and discussing such things as how to simplify restaurant menus and train sales people to recognize someone with dementia. The goal is to make Anderson a dementia-friendly community.

How to be a Friend to Someone Living With Dementia

- Educate yourself. There are many stages and kinds of dementia, including Alzheimer's, which manifest themselves differently in different people.
- Be there. Call and invite your friend to do activities you both enjoy, whether it's fishing, shopping or going out to lunch or to the museum.
- Ask what they are comfortable doing and what they need help with. They may need a ride or help mowing the lawn, shopping or cooking a meal.
- Talk directly to your friend, not to their spouse or partner. Make eye contact. Let them know it's wonderful to see them.
- Be patient. If someone asks a question repeatedly, don't point that out. Just answer. Give them plenty of time and space for responses. They may be working hard to think about what they want to say.
- Don't correct or argue if they say something that isn't accurate. That can add to feelings of embarrassment and frustration.
- Offer reminders. If your friend looks confused, give your name and connection. "Our kids played baseball together."
- Don't ask a series of questions, which can be confusing. Avoid questions like "What did you do today?" which require short-term memory and can be frustrating for someone with dementia. Better to ask questions that someone in any stage can answer and that show you care, like, "How do you feel today?"
- If going out, avoid loud, crowded places. They can be overwhelming.
- Touch is important. Hug. Offer a gentle touch on the arm or hand or shoulder. People with dementia sometimes feel others are afraid of them.

Write to Clare Ansberry at clare.ansberry@wsj.com