

What people with early-onset dementia want you to know

June 2 2022, by Dennis Thompson



An elevator encounter that happened to Laurie Waters highlights the

daily plight faced by early-onset [Alzheimer's](#) patients like her.

Waters, 57, was stuck in an elevator at an Alzheimer's convention with other folks who were growing loud and excited—and the situation was getting to her.

"I was starting to get panic-stricken, being in that enclosed space. And one gentleman was like, 'Well, what's the matter with you?'" Waters recalled. "I said, 'I'm actually living with Alzheimer's.' And this woman next to him said, 'You know, that's really mean to say that.'"

June is Alzheimer's & Brain Awareness Month, and people like Waters are taking the opportunity to share what they'd like others to know about what it's like to live with a dementia.

Her elevator tale illustrates two important lessons—[younger people](#) can have dementia and people with this disease would really rather *not* debate their diagnosis or be told they don't look like they have Alzheimer's.

"I look young, and people even in the Alzheimer's community who are around it still don't recognize younger-onset," said Waters, who lives in Clover, S.C. "It's everywhere. I've had doctors who have sat there, who haven't met me before, just look at me and be like, 'Are you sure you're diagnosed with Alzheimer's?'"

The frustration for Deborah Jobe comes from folks who talk about her as though she isn't there.

"My husband and I will be in a room and people will ask him, you know, 'She looks pretty good, how is she doing?'" said Jobe, 55, of St. Louis, who has an early-onset form of dementia called [posterior cortical atrophy](#).

"I'm like, 'Hello! Right here! You can ask me. It's OK. I don't mind,'" Jobe said, laughing. "I'm still here. I'm still human. Please address to me and if I can't answer, I'm sure he'll step in and help."

The upshot from Waters and Jobe—people with Alzheimer's are still people.

"One of the common themes I hear over and over again is that how the diagnosis does not define who they are," said Monica Moreno, senior director of care and support with the Alzheimer's Association, who works with early-stage families in the wake of their diagnosis.

"It's not uncommon that when people hear that someone has been diagnosed, they immediately think about the end stage of the disease, where an individual may not be communicative and may not necessarily be aware of their surroundings," Moreno said.

"And while we know that that may be that's where the disease leads to, in the early stage of the disease individuals still want to live a meaningful life and they know that they still have things to contribute to society," she said.

First signs of trouble

Waters received her diagnosis in 2017, when her husband noticed that she wouldn't quit working.

"I wouldn't leave my office. I used to work for a pharmaceutical company, and I used three computers in my office going through [patient records](#)," Waters recalled. "And I could fly through a patient's record in, like, five to 15 minutes.

"All of a sudden, it was taking me a half-hour, 45 minutes to an hour just

to get through one record," Waters continued. "My husband noticed I wasn't even coming out of my office for coffee or lunch or dinner. I was working eight to 12 hours a day just to get work done. And when I had to go into the office to train people, I couldn't even remember some of the people's names that I knew for years. It was horrible."

Jobe had to walk away from a high-powered career as a customer success manager for global companies following her own diagnosis two years ago.

"I would be in front of governance boards, executive management, to do a presentation and just find myself stopping," Jobe said. "Literally, the words were in my head but I couldn't get them out, or the wrong words would come out. And so I would joke and I would say, 'You know, I'm sorry, let me take a step back, I haven't had enough coffee today.'"

She also found herself struggling to keep up with new product updates, never mind explaining them to clients.

"I just couldn't grasp it," Jobe said. "I've been in this industry for over 30 years and I just couldn't grasp it. I would have to ask questions over and over."

Both women's lives are different now, as they've adapted to their illness.

For example, Jobe's husband uses laminated cards to help her around the house—"The dishes are clean," or "The stove is hot." Jobe can't drive or cook or ride a bike, and often forgets to eat.

But she still loves new technology and word games and creating art. She's still living her life.

"So don't treat me differently unless I ask you to in some way—meaning

like, OK, you know, slow down a little bit more," Jobe said. "I'm still me. I'm still who I am before. Some days, maybe it doesn't show. But the heart of me, and the soul of me is."

Patience and understanding

Jobe and Waters and other Alzheimer's and dementia patients have a few other things they would like others to know, to help make their lives less frustrating.

[Dementia](#) sometimes leads Jobe to act in ways that don't reflect her true self, for example.

"I do have bad days where I'm maybe more agitated or defensive or confused," Jobe said. "My husband sees these days coming up before I do. I get what he calls crazy eyes, and it starts before I realize that it's happening.

"So maybe I'm doing something that's out of character for me, but it's not because I want to do it to hurt somebody or get mad at somebody," Jobe continued. "Sometimes I can't help it."

People dealing with a person with Alzheimer's or dementia also can help by being very patient with them. Waters recalled a day recently where she couldn't for the life of her figure out how to scan a document.

"Now you're talking about somebody who used to work with three computer screens," Waters said. "I sat in my office for almost an hour and a half trying to figure out how do I scan this document into my computer. Couldn't do it.

"People are looking at me and I'm like, I have to now explain to all these people who are looking at me like, 'What do you mean you can't scan a

document? What's wrong with you? You don't look like you have anything wrong with you. You don't look like you have Alzheimer's. Are you crazy?" Waters continued.

Jobe agrees.

"I don't think as fast as I did before, which really frustrates me," Jobe said. "I'm like, give me a minute. Let me try to process it first, and then I can answer it. Or maybe I'll need you to break it down into something a little more simple."

The very best way that a person can help someone with Alzheimer's or dementia is by staying in touch and learning all you can about the illness, Moreno said.

"When the diagnosis is shared with others, it really does test relationships," Moreno said. "And it's not uncommon for friends to kind of step back and really not engage with the person living with the disease in the family anymore. And there really isn't a reason for that.

"A lot of times it's just because they don't understand the disease. They don't understand the progression," Moreno continued. "And if they just took some time to educate themselves, they can get a better understanding of the disease and how to support that individual—to stay friends with them and engage with them and help them live the best life they can for as long as they can."

More information: The Alzheimer's Association has more about [Alzheimer's disease](#).

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