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What's the best way to talk to someone with Alzheimer's?

By Susan Berger May 30 at 9:00 AM

During a routine trip to my local grocery, I ran into an acquaintance I had not seen in more than a year. She looked great and was her typically upbeat, energetic self. We exchanged hellos. I was not prepared for what came next.

“I was recently diagnosed with early-stage Alzheimer's,” she said.

This warm, accomplished, Berkeley-educated woman, a mother and grandmother who was my go-to person for local political goings-on, great books and recipes, then said, without skipping a beat, “I am doing okay right now, and I have signed up for a clinical trial.”

[*\[A few tips from experts for interacting with Alzheimer's patients\]*](#)

I hugged her and told her how sorry I was. Told her there are no words. In a daze, I finished my shopping. Driving home, I burst into tears.

It was many months later that our paths crossed again. I saw her across the room at our local synagogue. She was not close enough to say hello. In a way, I was relieved. Would she recognize me? And if not, what do I say?

According to the Alzheimer's Association, as many as 5.4 million Americans have the disease. For friends and relatives, there is the inevitable question of how to act.

“We know when we are friends with someone with Alzheimer's and interacting in a variety of settings, we may do our best to do the right thing and say the right thing,” said Ruth Drew, director of family and information services at the Alzheimer's Association. “But it may not always be the right thing.”

[*\[Alzheimer's warning signs\]*](#)

Drew said that Alzheimer's disease progresses more rapidly in some people than in others. Many who are newly diagnosed stay in the early stage, retaining their personality and people skills, for quite a while, but for others, serious changes happen more quickly.

Christopher Marano, a geriatric psychiatrist at Johns Hopkins Medicine, said that the interval between the initial diagnosis and a significant downturn can range from five to 20 years but that “people who are diagnosed at a younger age tend to progress faster.”

That woman I met at the grocery is now 73 years old and was happy to talk about how she wants the world to deal with her now.

‘I felt scared’

“When I first heard it was Alzheimer’s [about three years ago], it was like ice water on my face,” she said. “I think I felt kind of scared — just not sure what is next.”

[Keeping mentally active doesn’t stave off Alzheimer’s disease — only its symptoms]

She said she has a core group of girlfriends who treat her as before — including her in their plans for lunches, dinners and outings to art galleries and museums. “One comes and does crosswords with me, another comes and takes me to lunch. They know I have Alzheimer’s, and they don’t care.”

My friend has been open with friends and family since the day she was diagnosed, though she and her husband, who live in the suburbs of Chicago, did not want to be identified to a wider audience. Her husband thinks the openness with those she knows works for her. “If it was secret, that would be a burden for her,” he said.

And while she said she is for the most part still okay, her husband reminds her that there are times she turns to him and asks, “Am I losing it?” or “Am I out of it?” And she did say there are things she is sad about. “It bothers me. I love to bake. I can’t bake anymore. And I can’t cook alone anymore. [Her husband helps her.] I feel really bad about that.”

When she is down and asking “what is going to happen to me next,” she continued, her husband always says: “We don’t know what is next. And we are all going to die someday. Let’s just make this a good day.”

[Two minutes playing this video game could help scientists fight Alzheimer’s]

The support her husband provides is clearly key. When I comment on how great she looks — so put-together — she laughs. Not long ago, her husband went with her to Neiman Marcus to see her favorite makeup artist. He told the artist that his wife has Alzheimer’s and asked that she make over his wife while he paid close attention. “I watched. I took notes and typed them up,” he said. “And now I do her makeup. It’s good I have time.” (He is a recently retired lawyer.)

Open about diagnosis

Her daughter said she believes her mother’s decision to mention her diagnosis when it was not yet apparent that her memory was failing has made it easier for others in social situations. People know the diagnosis but don’t yet encounter a person who is very different. “My mom is and has been open and honest about her diagnosis, her journey through the disease and about managing the symptoms,” and so people feel comfortable talking to her about it. “She never tries to hide it and speaks about it easily when someone asks how she’s doing.”

But for my friend, as with all Alzheimer's patients, the disease inevitably does change relationships as memory, language and the ability to manage independently fail. Figuring out how to interact can be challenging at that point, Drew and other experts say.

It is natural to want to pull back when someone seems to not recognize you or be confused in other ways, Drew says. But it is important to remember that the person with Alzheimer's (and their caregivers) often feel isolated, lonely and sometimes hurt that people they have been so close to begin to shy away.

Drew and other experts advise taking cues from the person coping with the disease. If a newly diagnosed friend looks confused after you say hello, immediately say your name and mention how you know one another. ("Our kids went to school together.") But these reminders shouldn't feel like a test or a quiz (Don't say: "Remember? Our kids went to school together.") Tell the person, "It's wonderful to see you."

Drew recalled a man who had offered to volunteer with Drew's organization. The agency paired him with a man with Alzheimer's who loved to golf. The two began golfing together once a week. Over time, the latter went from being an excellent golfer to barely being able to play.

"But he didn't care," Drew said; he looked happy and clearly enjoyed being outside. "They drove around in a golf cart on a beautiful day and had a wonderful time. The outings were so meaningful. They made him feel regular — that he could still enjoy the things he enjoyed."

Marano suggests that relatives or friends of people with Alzheimer's take the lead from the patient, even if it seems repetitive or not focused.

"Go where the person takes you," Marano said. "If you are worried they won't remember you, just say, 'Hi — it's Susan. How are you?'"

People with Alzheimer's often seem quiet, especially in groups. Marano said they probably are having trouble keeping up with multiple conversations. In that case, it is helpful to gently lead them along: Fill them in quietly with details or names they may have forgotten so they feel they are part of the group.

Drew agrees that taking cues from the behavior and reaction of someone with Alzheimer's is essential. If a person looks confused when you say hello, mention your name and how you're acquainted.

Rachael Wonderlin, director of dementia care at an assisted-living facility outside Pittsburgh, said that family and friends find it especially difficult to figure out how to interact with an Alzheimer's right after the diagnosis.

"People with dementia live in a different world than we do," she said. "It is up to us to embrace their reality. It's often hard to do."

One of the hardest occasions is when the Alzheimer's patient asks for someone — a parent, friend or child — who has died. This is common, Wonderlin said, because the loved one was deeply embedded in their memories.

Too often, people respond to this by trying to force a memory, saying, for example, "Daddy died five years ago." But doing that, Wonderlin said, is like delivering bad news over and over again, since the information is coming in as news each time.

Drew said she knew a woman with Alzheimer's who was delightful and retained her charm as her disease progressed. Her two daughters — both bright professional women — cared for her. And they decided early on that they had never lied to her and wouldn't start now.

Every day, the woman wanted to know when Daddy would be home. They always told her that Daddy had died and described the circumstances of his death. Each time, their mother would cry. Once, they even took her to his gravesite. "It was terribly traumatizing," Drew said.

Eventually, the daughters recognized that they needed to come to terms with their mother's reality, even if doing so felt like lying. When their mother asked about their father, the daughters changed the conversation and would say, "Daddy's out tonight, but we will see him soon."

Wonderlin says friends and relatives of Alzheimer's patients can be put into three categories:

- Those who get it immediately. They understand that the person with Alzheimer's has a different reality and they need to "get in their world" and adjust their conversation accordingly.
- Those who don't understand initially but learn that it is easier to agree than to argue.
- Those who don't get it. They fight with the person and argue instead of realizing that they need to fix the way they talk.

Wonderlin said many people have trouble adjusting their interactions.

"They just can't wrap their heads around it," Wonderlin said. "They don't want to lie."

Practical assistance

For someone newly diagnosed with Alzheimer's, Wonderlin said, emotional support more than anything is key because people are often shocked, depressed and worried about what will happen to them. And practical assistance can be helpful in that early period, when someone may just need some simple cues to manage: Label drawers, for example, and assume that the person can continue doing his or her usual tasks.

"Some people get set aside," Wonderlin said, and this can be frustrating or demoralizing. "It is best to assume the person can manage the task, and if they struggle, then give assistance."

As the disease progresses, the emotional support can be as simple as just keeping someone company.

Reading to them, talking a walk and listening to music together can be comforting.

Drew said she knew a patient who could no longer hold a conversation but still recognized hymns at church. “She could still remember the music,” she said. “Her eyes would brighten — she was tapping her toes and came alive.”

Drew said pets often are great sources of companionship for someone with Alzheimer’s. The Alzheimer’s Association notes that a visit from a pet can often cause a patient to “transition from stoic and emotionless to animated and joyful.” But the association also cautions that dementia patients can be unpredictable, with different reactions to a pet visit. Time of day is also important — and not just for pet visits — because many patients experience “sundowning,” a term that refers to an increase in memory loss, confusion and disorientation that the end of the day sometimes brings.