Unlocking the Silent Prison: Caregivers are learning a better way to communicate with Alzheimer's patients

by Christine Wicker

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Eighty-year-old Mary studied her only daughter's face intently. "You're not my Susan," she said.

Susan cried as she recounted the incident to Michelle S. Bourgeois, a speech-pathology professor at Ohio State University who is an expert at communicating with people who have dementia. That's when Bourgeois suggested that Susan create memory flashcards. "Your mother will never forget you," Bourgeois told her. "She just needs help remembering." The next week at the nursing home, Susan said, "Mom, I have a gift for you" and gave her two photos. Under one she'd written, "This is my daughter Susan at age three"; under the other was "This is my daughter Susan now." Mary studied the photos, then looked at Susan and said, "As beautiful as ever."

Bourgeois is part of a group of scientists whose work marks a sea change in how caregivers deal with people who have dementia, focusing on what they can do rather than on what they've lost. "People tend to treat these patients as if they're not the persons they were," says John Zeisel, president of Hearthstone Alzheimer Care, Ltd., whose six residences use Bourgeois' techniques. "But they're still here."

Bourgeois' work grew out of her Ph.D. research in the 1980s, when she developed some of the first memory books, which use pictures and sentences to help people with memory problems -- including Alzheimer's patients -- recall past events. Alzheimer's disease, which affects up to 5.3 million Americans, first strikes the hippocampus, the part of the brain that is critical for learning and memory processes. Typically, long-term memory and certain kinds of skills like reading (which is overlearned so it is automatic) are less afflicted. "Even when dementia is so advanced that people cannot speak, they can read if the words are large enough," Bourgeois explains. "We know because they smile, make pleasant sounds, and stroke photos of loved ones with captions." In contrast, she says, "Spoken words literally go through one ear and out the other. Patients understand, but they can't store the memory. That's why they ask the same question again and again."

A woman at one of Bourgeois' lectures reported that her father would repeatedly ask, "Where are we going?" during their weekly drives to the doctor. Bourgeois advised her to answer his question -- and also write it down on a notepad and give it to him. When he asked again, she should say gently, "The answer is on that notepad." When the woman tried this out, she said that her dad looked at the notepad, out the window, and back at the notepad. After that, he stopped asking, "Where are we going?"

Similar techniques have been used to deal with anger and anxiety in people with dementia. When a patient refused to shower, Bourgeois told her nursing aide to make a card that read, "Showers make me feel fresh and clean" and give it to her after saying it was time to shower. The technique worked.

With a grant from the Alzheimer's Association, Bourgeois hopes to next dispel the belief that Alzheimer's makes people miserable. Using pictures with captions, she is asking patients about their quality of life. "We find that if caregivers aren't stressed and in a hurry, if the patient is well cared for, and if they feel safe and in a good environment, they think their lives are good," she says.

Bourgeois has taught thousands of caregivers her methods, and they've taught thousands more. When she discovered over 20 years ago that memory could be reclaimed with simple tools, she set herself a high goal -- one she still holds: "I want families to remember these as happy times in their lives."

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