



Scientists bond with Alzheimer's patients

Program pairs researchers with people in early stages of brain disease

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CHICAGO - Peering through a microscope at brain cells from mice with Alzheimer's disease was about the closest scientist Sarah Cole had been to the mind-robbing illness — until she met Jenny Knauss.

Picturing a debilitated shut-in, Cole instead found a vibrant, active Oxford-educated grandmother who has become a cherished friend.

The partnership is thanks to an unusual educational program that pairs researchers and medical students with early-stage Alzheimer's patients, a group growing in numbers whose needs the medical community is just starting to address.

Over nachos and beers with her husband and Cole at a Chicago restaurant, Knauss, 68, said the program has helped keep her active and avoid focusing on the downside of Alzheimer's.

Cole, 29, said meeting Knauss has introduced her to the human side of the disease and shown her that the diagnosis doesn't have to stop patients' lives from being fulfilling.

"We don't really worry about what she can't do," Cole said. "We just worry about what she can do."

Increased awareness about Alzheimer's disease has led to earlier diagnoses, and many if not most of the more than 300,000 Americans diagnosed yearly are in the early stages of the disease, according to Kathleen O'Brien of the Alzheimer's Association.

These patients might have difficulty using cell phones, navigating automated telephone menus or making change but can live several years before becoming incapacitated by the mind-robbing illness.

Day care or residential centers for patients already debilitated by Alzheimer's disease are relatively plentiful. But O'Brien said early stage patients are "very much of an emerging and growing and urgent group for us to recognize because many of them are not being served in a way that can be helpful to them."

The Northwestern University program will be spotlighted at an Alzheimer's Association conference running Wednesday through Friday in Chicago.

Across town, the University of Chicago has a similar "buddy" program with dual goals — to give the medical community better insight into Alzheimer's and keep patients engaged in activities that help them cope.

A rare, familial form of the disease that can strike when people are in their 30s and 40s is called early onset Alzheimer's. Early stage patients have the most common form of the aging-related disease.

Dr. David Bennett, an Alzheimer's specialist at Chicago's Rush University Medical Center, said that when he began seeing Alzheimer's patients almost 20 years ago, "it wasn't unusual for people to come in for their first evaluation very severely impaired. Now it's actually quite unusual."

Most Alzheimer's drugs, designed to improve mental function, are designed for use in early stages but do not slow the underlying course of the irreversible disease, Bennett said.

'A rock off my shoulder'

Some scientists believe mind-stimulating activities like crossword puzzles and taking classes might help prevent — but not treat — Alzheimer's. Researchers are studying whether more structured memory-stimulation programs might help early stage patients learn tasks that might help keep them independent longer, said Neil Buckholtz, head of the dementias of aging branch at the National Institute on Aging.

In the meantime, Bennett said programs that keep patients engaged in the community, like the buddy program, "are good things to do even if they don't impact the course of the disease."

Darby Morhardt, a social worker who helped create the program at Northwestern, said it is indirectly therapeutic for patients by providing educational and social support.

Knauss headed the Illinois Caucus for Adolescent Health when frustrating memory lapses began slowing her work and made her increasingly agitated.

She said the diagnosis in May 2002 "was sort of a rock off my shoulder. I no longer had to worry about what I had. I just had to find out more about this thing that had come into my life."

She joined Northwestern's Buddy Program six months after her diagnosis, paired first with a medical student who remains her friend. In 2004, after that yearlong stint ended, Knauss got her second partner, Cole, a fellow Brit who coincidentally was married in the same village near Cambridge where Knauss was born.

Cole's research involves examining diseased mice brain cells "to pick up clues to the underlying pathology."

"I've been working on Alzheimer's disease maybe four years now and I don't know anyone with Alzheimer's ... or I didn't. I had absolutely no idea what it's like living as a patient," Cole said.

The women often visit museums, attend lectures or just gab over beers.

Alzheimer's "is what brought us together. We acknowledge it, but it doesn't define anything we do," Cole said, calling their friendship "a phenomenal thing."

"It's really, really important for people my age to interact with younger people," Knauss said, smiling at Cole from across the table. "I've found it absolutely terrific to, for example, spend a lot of time with you."

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