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ONE CLINICIAN'S SEARCH FOR THE PERSON BEHIND THE 'DEMENTIA'

By **DORIS BERSING**

It was a sunny Saturday in San Francisco when I arrived for my first day on the job. I had no idea how my personal and professional life was about to change. A clinical psychologist, I was just starting my rounds at Hayes Valley Care, an innovative assisted living facility founded by Nader R. Shabahangi. The facility is one of the AgeSong Senior Communities that won the American Society on Aging 2006 Business and Aging Award for small businesses.

Within minutes, I met James Eddy, one of the older residents. An 89-year-old African American, Mr. Eddy walked with a cane, which he used to threaten anyone who tried to stop him from leaving the facility. One day, for example, he hit Pablo, a tall staff caregiver who tried to make him understand that he couldn't leave.

NEW TO DEMENTIA

Mr. Eddy seemed disoriented at times, looking left and right, seeming to look for familiar cues and asking, "Where am I?" Although I'd been a therapist for 25 years, I had little experience with age-related dementia. Moreover, being a foreigner, I was a stranger to American culture, to this facility and, most important, to Mr. Eddy's world.

In his thick Texas accent, Mr. Eddy kept repeating how hard he worked. I thought about why this particular memory remained after the other memories of Mr. Eddy's life seemed to elude him. When I got old, would I—as a workaholic—remember only my working hard? What a scary thought.

"Aren't you retired, Mr. Eddy?"

"Yes, but I still work pretty hard," he replied. "Don't you see how hard it is?"

Over time, I listened to Mr. Eddy rant and rave about what a hard worker he was, and I wondered about his condition. I did not get it.

Between Mr. Eddy's heavy Texas accent and my Mediterranean one, complicated by his repetitious statements and hearing loss, communication was a struggle for us. Rarely in my professional life have I felt so inadequate.

I had many questions and few answers: How could I help Mr. Eddy put his work life behind him? How could I help him relax—and at the same time assist him in seeing reality more clearly? How could I do my job, the job I'd been doing for the past quarter-century?

FEELING INSECURE

As a clinician in the humanistic tradition, I wanted to try meeting Mr. Eddy where he was. But where was he? I located his chart and read it with interest. I understood the medical terminology, the diagnosis: Mr. Eddy was afflicted with a 290.43—the clinical code for vascular dementia. He had had several strokes, and suffered from severe hearing loss.

Although I was well versed in many types of mental illness, I felt insecure about my ability to treat

dementia. I decided to do some research: I read books in an attempt to demystify the subject. More important, I knew, was to try to establish a therapeutic relationship with Mr. Eddy. I wanted to help him understand and cope with his reality, to comfort and help him find meaning in this phase of his life.

While doing my research, I was struck by how little science knows about dementia. I found plenty of descriptions of the physical symptoms at different stages. But mostly I gleaned a sense of how impotent the medical profession feels in the face of this rapidly spreading phenomenon.

According to the American Medical Association, dementia is associated with memory and thinking impairment—problems with vocabulary, abstract thinking, judgment and physical coordination—that lead to a decline in social skills and an increase in confusion, all suggestive of brain disorder. Those afflicted with dementia may also suffer from apathy and depression, delusions and hallucinations. In general, this condition, which can strike at any age, progressively gets worse and is irreversible. Some dementia disorders respond to treatment, but many do not.

I felt burdened rather than enlightened by all this information. None of what I read accounted for Mr. Eddy's intense look, his formidable presence. Everyone is unique, I reminded myself. For the most part, Mr. Eddy seemed lucid, and he certainly wasn't apathetic. I could understand how the medical establishment might define his state as delusional, but I sensed something more. Mr. Eddy was so strong, so firm in his opinions, so sure of what he said. To me he seemed vital and full of life, not declining or lethargic.

TRYING TO CONNECT

And so I decided to take off my scientist hat and just be there as a fellow human being for Mr. Eddy. Little did I know the struggles that lay ahead. I began meeting regularly with him, trying to connect, not just on the verbal level—with our clashing accents and his hearing loss—but on the nonverbal level, too. We used to sit in silence, sometimes holding hands, making eye contact for as long as one hour.

Because he couldn't answer my questions or I didn't always understand his answers, I spent the time telling him stories, such as tales of my travels or how I got to the United States. We talked about baseball and his life in Texas as a public-works laborer. I learned why he talked so much about hard work—but most of the time, I just felt ignorant and powerless.

Once—and only once—I told him that my father and I loved horses. We had a few on our ranch, and I said that it saddened me to see them get sick or die. As with all my stories, Mr. Eddy seemed lost in thought, absent. I assumed he simply wasn't listening.

Then, one day after many months, after countless attempts to connect with Mr. Eddy, I showed up for another of our Saturday sessions. I had just suffered a personal loss, and it showed on my face. As I approached Mr. Eddy, he looked me in the eyes, raised his hand as a stop sign, and said, "Has one of your horses died, because you look very sad?"

I was speechless. How had he known? Not only had Mr. Eddy been listening to me, he had stored the information somewhere. Then he had used remarkable powers of perception to read and interpret my countenance. All this from a man pigeonholed as demented, apathetic and delusional.

THE 'DEMENTIA' LABEL

How, I wondered, could I call myself a clinical psychologist if I could not make sense out of this experience? I vowed to remain with Mr. Eddy, to let him teach me about the phenomenon known as dementia.

With the help of mentoring by Nader Shabahangi, I began to understand his view that those labeled as "demented" simply dwell in a different reality. Instead of embracing consensus reality, they tend to dwell in "dreamland" or in that intangible "essence" also called spirit. It was clear to me that Mr. Eddy was still there. Perhaps he had checked out from consensus reality, but he had not separated from his dreamland or essence. He could still express his needs, beliefs and feelings. In this way, he could tell us who he was. Behind this label of "dementia" was a person, his essence unfolding at every moment.

Thanks to Mr. Eddy, who died in 2003, I found a new passion after 25 years of international professional practice in clinical psychology. He taught me that people with "dementia" are not necessarily demented—and if we would learn a different language, we can communicate and understand the richness of their experience. Now, when I see people so labeled, I listen carefully to what they say, to the meaning behind their words. I listen to the language of dementia, forgetting the label and seeing the person behind it. ❖

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