Waking up to Narcolepsy

Retired nurse receives award for raising awareness

COURTESY OF BILL JOHNSON '73

Bill Johnson '73 — here with his wife, Charlotte, and their granddaughter, Lorelei — says it might be hard for college students to recognize they have a sleep disorder because of their lifestyles. "You are burning the candle at both ends. If someone had told me in school, you have a sleep disorder, I would have laughed."

Every year, **Bill Johnson** '73, a retired Army nurse, stands up in front of the medical students at Duke University and explains what it is like to live with narcolepsy. Sometimes he explains the situation one-on-one to someone who will face the same challenges he has.

"Last year, we met a med student with narcolepsy," Johnson says. "He didn't ask, but you could see it in his eyes: 'Am I going to get through med school and end up like you?' "

For his efforts to spread the word about living with narcolepsy, last October Johnson received the Public Education Award from the Narcolepsy Network.

That he can stand up and speak to a group at all is a major accomplishment. His wife, Charlotte, often accompanies him because his symptoms include cataplexy, in which he simply goes limp. Johnson describes a typical episode at the grocery store: "I was going into the store, and I couldn't move. I couldn't get the cart through the door."

Johnson controls his symptoms with the prescription drug Xyrem. That's what pushed him to speak out. In the 1980s, there was a move to ban the active ingredient in Xyrem, a form of gamma-hydroxybutyrate. Johnson was in clinical trials for the drug, and it was making it possible for him to continue in his job. He went to Chicago to speak to an approval panel. "At that time, I had been taking Xyrem twice a night for more than 10,000 doses," Johnson says. "The cataplexy was controlled. There I am standing up in this room with all these really hostile people, and I was able to ask my question."

Johnson says it's hard to pinpoint his onset of narcolepsy. He remembers taking a history of religion course at UNC in which he had read all eight books assigned for the midterm but at the end of the exam, he looked down at his blue book and it was empty. He suspects he had fallen into micro-sleeps, another symptom. "I wonder about college students," Johnson says. "You are burning the candle at both ends. If someone had told me in school, you have a sleep disorder, I would have laughed."

— *Susan Simone*

See What Narcolepsy Is Like

There is no cure for narcolepsy, but the earlier it is diagnosed, the better the treatment outcomes. Awareness is key. Bill Johnson encourages people to search for "cataplexy" on YouTube to see how symptoms can present themselves.

Symptoms of Narcolepsy

Excessive daytime sleepiness (EDS) and micro-sleep: The person will fall asleep no matter what is going on and often not notice he has fallen asleep. Bill Johnson has visited the school where his wife, Charlotte, teaches. He can help see the difference between a child who is tired and a child who might be in the early stages of narcolepsy. In addition to dosing off, twitches and jerking motions can be the first signs of micro-sleep.

Cataplexy: Any emotion can trigger an episode of cataplexy, in which the body goes limp and the person slumps over and falls. For Johnson this has happened laughing at the *Crocodile Dundee* movie or hearing about the murder of Eve Carson '08, the UNC student body president. "I didn't know Eve Carson, but every time I heard about her on the news, I found myself so moved. It was like it happened personally and that triggered the cataplexy."

Hallucinations: There can be visual and sensory illusions that are extremely vivid. They can be dangerous because the person is convinced that what he sees is real. "My wife said that's the one thing she would leave me over — if hallucinations are not controlled. One night I brought my daughter down the stairs because I thought the house was on fire."