

Let Me Tell You...About...Um, I Forgot!!

By Kathleen Hall

Boy, this hits hard, doesn't it? Even before I was diagnosed with multiple sclerosis, I was having problems with remembering, concentrating, following a conversation, and associating the correct names with things. "Would you please go into the truck and get the seeds?" Unfortunately, the truck was really the refrigerator and the seeds were actually milk. My family and I would laugh out loud—but deep inside I wasn't laughing.

I thought I was losing my mind. It was difficult to explain to others what was happening when I didn't know myself. I do remember the fear and loneliness that went along with all this. I silently begged God, "Do what you will to my body, but please leave my mind alone." I meant every word.

After my diagnosis with MS in 1980, I found some articles about memory loss and cognitive problems. But they all said that these symptoms only appeared in later stages of the disease. Wait a minute. I could still walk reasonably well. I could still see (with my glasses on). I was shopping, cooking, cleaning, and paying the bills. Had my mind bent so far that I was only imagining my cognitive problems? After repeatedly flying over the cuckoo's nest, had I finally landed?

Years passed, with no change for the better. In fact, my MS slowly worsened. I was able to speak to family and friends a little more freely about what I perceived was happening to my mind (in jumbled English sometimes!). If my thoughts were words on a piece of paper, they would no longer be in regular type. My thoughts and ideas seemed to appear as faded print with missing sentences. I wondered if the words would totally fade someday, but I would no longer be aware of it. I was frightened to death about this loss of control.

My doctors pointed out that the stress of living with MS (or any chronic disease) can cause problems with memory. One friend told me that I was

doing too much. Another told me to get out more—“Keep you mind active.” And I loved this one—“It happens to everybody. You’re just getting older.” At 33? Oh boy, I couldn’t wait to turn 34.

Depressed people liked being around me because I made them laugh. Webster himself would have died laughing at my nonsensical word definitions. I seriously thought about going into stand-up comedy, although I wouldn’t be standing up actually. The legs were getting weaker, so I was using a wheelchair now.

More years passed. One night I was sitting at my computer, visiting an MS chat room and the topic was—cognitive problems and MS! After all those years doubting my own sanity, I finally realized there were other people with the same problems that had made me feel so fearful and so embarrassed.

That night, someone from the chat room directed me to an online article about MS and cognitive problems. I grew wings. As I read, the tears flowed. I wanted to wake my husband and scream, “Look—I’m ‘normally’ abnormal!”

In past decades, cognitive problems were considered a rare symptom in MS, but recent studies have shown that more than half of us will have some kind of cognitive impairment. Some of these difficulties may be attributed to the disease, but there can be other causes, including medications. I’ve realized it’s important to discuss all my concerns with my doctors.

Some days are much harder than others. When I am asked to “hurry up,” even my name can become a memory. I guess we’ve all gotten used to the idea of my cognitive problems being permanent, but I do miss the sharpness of mind I once possessed. On the positive side, my doctors have become more aware of the cognitive difficulties resulting from MS, thanks in part to the many informative articles recently published on the subject. (Did I mention that I have access to a photocopier?)

I also rely a great deal on sticky notes. I bought them in several colors, hoping to color-coordinate my life--but I forgot my reasoning behind the different colors. My home office does look like a rainbow, and I'm still going forward--hanging onto my sense of humor.

Kathleen Hall was diagnosed with MS over 20 years ago. She writes articles and poetry, and speaks publicly about MS issues.