

Telling the World

I had accepted the position of associate chief of staff for ambulatory care and made plans to move once school for the kids had ended. A month later, I was told that I had multiple sclerosis. When I asked about my long-term prognosis, the answers were vague.

"It's an unpredictable disease," they said. "Some do well. Others experience a relentless downhill course. However, you have many favorable signs. You'll probably do relatively well."

I logged on to PubMed to check the literature for myself. What I read was depressing. I confirmed that no cure has been found. Although treatment may decrease the frequency of exacerbations by one third, the most effective therapy left many with flu-like symptoms for 24 hours after the injection and cost \$1000 a month. That's a lot of money and substantial side effects for merely a possible benefit. After 10 years, one third of people with multiple sclerosis require assistance walking and one half can no longer work. However, my neurologist had said I had many favorable signs. We moved to Iowa.

Every morning I jogged, took my injections, and then went to work. I saw patients, taught residents, and worked on developing our department. My family prospered. When running became too difficult, I put in a pool and switched to swimming.

But whenever I saw veterans using their electric wheelchairs, I wondered whether that would be me some day. Would I become wheelchair-bound, a burden to my family? Dark thoughts began to intrude, especially at night. I tried to hide them. After all, my kids were watching, and I knew that they would absorb the choices I made. How could I let them see me give in to despair?

I discovered the meaning of fatigue. Evenings I was tired, very tired, too tired sometimes even to have supper with my family. My back pain increased and walking was exhausting. Others began to notice. Initially, I shrugged off the inquiries about my limp. Then, I was wiped out by midafternoon. I switched my desk chair for a chemo chair. It helped, a little.

My physician sent me to prosthetics for a brace, which I kept discreetly hidden under long socks and trousers. A few months later, he gave me a prescription for a scooter. When he changed his mind, telling me it would be better for me to get a tilt-recline wheelchair, I was even more dismayed. Was I going downhill that fast?

My eyes filled, and tears fell silently, betraying my pain. In a former life, I had run marathons. I had taught Tae Kwon Do; I have a black belt and even competed nationally—but that was a lifetime ago. The image of me in a wheelchair wounded me, but I knew that I could not keep rearranging my days to avoid walking.

What would I say at work? After ordering the chair, I called my friend John, one of the few physicians in whom

I had confided about the multiple sclerosis. When I told him I had ordered the wheelchair and that I dreaded telling the staff, he offered to help.

"I could mention you have MS at work. It wouldn't take long for the news to get through the whole department."

Yes, that would have been easier, but it would not have been right. I declined his offer. I made the announcement the following Wednesday at the provider meeting, which included our remote clinics listening by phone.

"On Friday, those of you who are on the main campus will notice that I will be using an electric wheelchair to get around the facility."

Their faces all turned toward me.

"I need it to manage the fatigue related to multiple sclerosis."

Shock and concern were everywhere. Apparently my attempts to hide the multiple sclerosis had worked. They really had not known.

"It should not have a major impact on the department."

Afterward, one by one, physicians came by my office to talk. If I wanted to continue leading the department, I needed to remain confident about the future.

"I had no idea."

"You look so good."

Each time I smiled, and said, "It will help me manage my fatigue more effectively. I plan to continue to work and run the department; nothing should change. It'll be fine."

My heart however, was not as confident as the words I used. Friday, the wheelchair arrived. And then the difficult questions came.

"Who will lead the department when you can't?"

"How much longer do you think you'll be able to keep working?"

When I began using the wheelchair, everyone in the hospital became aware of my disease. It was painful, seeing their faces, responding to their shock.

"What happened to you?"

"Are you OK?"

I would take them to my office or to an empty room. Again and again, I smiled. Over and over, I said I was fine. Over and over, I said that being forced to use the chair would not affect my work. It was exhausting, all that pretending. Yet by the third day, the answers rolled off my tongue more easily.

Driving with a joystick was not easy, particularly in the beginning. The first time I stopped to speak to the clerks, I got into trouble. When I started backing the chair away from their station, it caught the corner of their desk, dragging it with me. I stopped, went forward a few inches, redirected the joystick, and tried again and again. Eventually the clerks came to my rescue.

As they disentangled my wheelchair from their desk, I said, "I guess you'll need to watch out for me. As you can

tell, my driving is not yet the best.” I laughed and so did they. Going around to the other clinic that day, I retold the story, warning my staff about my driving and how I needed a special driver’s education class for driving with a joystick. We laughed a lot, the staff and I, and although walking was still difficult, my days felt easier. It was not that my wheelchair had improved my energy that much, nor that I had gotten stronger.

The nature of my illness did not change; my strength continued to slowly slip away. I gave up being chief of ambulatory care, but I still saw patients and taught trainees. They were sharp and always knew the latest drugs and tests. Yet despite all that impressive clinical knowledge, very few understood how words and laughter could be far more powerful than the medicines they prescribed. They rarely understood that the healing necessary for living with a chronic illness typically comes from within—that the words we use for self-talk; how we frame our lives; and our ability to find humor in life’s circumstances, however dif-

ficult, either lead us to retreat from life or to remain fully engaged in living.

I did not ask for this. Nor did I want to have multiple sclerosis. It has, however, given me a great deal. From living with multiple sclerosis, I have learned about the fear and despair patients face, along with the drive to find hope—wherever it may lie. I have gained perspectives and insights that were often profound, ones which I probably would not have attained had I never been ill. For all of that, I am grateful.

Terry L. Wahls, MD, MBA

Veterans Affairs Iowa City Health Care System
Iowa City, IA 52246

Requests for Single Reprints: Terry L. Wahls, MD, MBA, Veterans Affairs Iowa City Health Care System, 1W42, 601 Highway 6 West, Iowa City, IA 52246; e-mail, Terry.Wahls@med.va.gov.

Ann Intern Med. 2008;149:61-62.

PERSONAE PHOTOGRAPHS

Annals of Internal Medicine invites submissions of Personae photographs for our cover and offers a \$500 prize for the best photograph submitted each year. Personae photographs are pictures that catch people in the context of their lives and that capture personality. We prefer black-and-white print submissions but will accept color, slides, or digital files. Please submit photographs or questions to Dr. Christine Laine (claine@acponline.org).