

Outward appearances



The public face of multiple sclerosis is very different than the private one.

by Scott Rice



Scott and Donna Rice have remained strong throughout the course of Donna's MS. Photo

courtesy of Scott and Donna Rice

Thirteen years ago, the love of my life was diagnosed with multiple sclerosis. Knowing very little about the disease at the time, we were thrown into a whirlwind of confusion and uncertainty. Real friends showered her with love and support while others showed their true colors and abandoned her as if she were contagious. Luckily for me, I married an incredibly smart, determined and downright stubborn woman.

My wife, Donna, does everything in her power, both emotionally and physically, to avoid showing that she is a victim of this progressive, debilitating disease. She has never been the “woe is me” type, and ever since she was diagnosed, she has kept her composure publicly, vowing to stand tall and confident, just as she always has—emphasis on the term, “publicly.” It’s mainly her close friends and immediate family who know she lives with MS. But there are still those few who, when they discover her situation, utter a phrase she has come to loathe: “Well, you don’t look like you have MS.”

That phrase, however, raises a good question: What DOES MS look like? What do people expect to see when they hear that someone lives with MS? Do they need to see a cane, a walker, a wheelchair? Some people with MS do need such assistance, but Donna is not there yet and might not ever be. But just because she does not show outward appearances of having MS, does that mean she doesn’t suffer on the inside?

The unseen struggle

It’s difficult for people to understand that Donna wakes up each morning and lies in bed for an hour, crying and praying because it feels like she has 30-pound sacks of sand on each limb. Friends and family wonder why we don’t take vacations with them any longer. It’s because she feels as though she wastes half their day waiting for her body to function and she doesn’t want to feel guilty for it. Just waking up at 5:30 a.m. to get ready so she could watch her daughter graduate from college and her son graduate from boot camp took every ounce of energy that she could muster, leaving her no strength for the remainder of their special days.

No one can see what a struggle it is for her to sit and eat a meal for a half hour, hoping she doesn’t drop her fork or glass and then worry if her legs will function when she stands up after sitting for so long. They laugh when she face-plants in the middle of the parking lot because her brain forgot to tell her leg to take the next step. They have no idea that she’s scared to death to hold her future grandchildren for fear of dropping them, and she cries inside knowing that she won’t be able pick them up to feed them, change their diapers and be the fun grandma she wants them to see and love. No one notices her immediately scope out the location of the nearest restroom every time she goes into a new restaurant. They don’t know that she has to practically perform a surgery-like sterilization just to self-catheter in a public restroom because the connection between her brain and her bladder has short-circuited.

Three years ago, her body rejected her latest MS medicine, virtually wiping out her white blood cells and lymphocytes. Her doctor told her to stop the medicine, saying it should only take one or two months for the counts to get back to normal. Three years later, they have barely risen, and now she's in constant fear of catching a "bug" because of her weak immune system.

By no means am I vying for sympathy or pity for my wife. That is the last thing in the world she would ever want. Donna is still the strong, beautiful woman I married 32 years ago, and I believe that her stubbornness has been her best medicine in dealing with this disease. But maybe by reading this, those who know nothing about MS will gain a better understanding that the effects are not only visible on the outside, they can sometimes be even more devastating on the inside.

Scott and Donna Rice live in Issaquah, Washington. Donna was diagnosed with MS in 2005.

Learn strategies for addressing the challenges that MS can bring by contacting an [MS Navigator](#) at 1-800-344-4867.

Read more about approaches to many [MS symptoms—including invisible ones](#).