Why You Should Have Friends With MS

by GERARD BLINK

A Friend From out of the Blue

Recently after I went on long-term disability due to multiple sclerosis (MS) in 2002, I received an email out of the blue from a woman in Queens, New York. I live in Toronto and she had seen my name on an MS support page. Actually, she wasn’t absolutely certain where she has seen my name.

Nonetheless the woman, named Cassie, explained she’d had MS since her mid-teens, so it had been in her life for over 20 years.

Finding a Connection

We started communicating back and forth. Her MS was far more of the cognitive variety, whereas mine was definitely more physical.

Cassie’s short-term memory was essentially gone: she literally couldn’t remember anything we’d discussed, even the next day (or later that day even), and pretty frequently she would not be wearing matching shoes. Our running joke was that she was a goldfish because they are reputed to have no memory, so every time they swim around the tank it’s like a new experience.

My MS was very physical. At that time I was using a cane to walk and my physical strength had taken quite a big hit too. I had a variety of other physical issues as well, from blinding nerve pain, to double-vision — none of which Cassie was dealing with. If you look at the list of potential MS symptoms, I have experienced most of them.

So there we were, two people with vastly different forms of the condition, in two different countries, yet we became fast friends almost immediately.

In truth, while we are so incredibly different, we essentially walk in the same shoes. We are people whose daily lives are dramatically affected by this horrible disease, and that was enough to establish an incredibly wonderful friendship.

Complete Understanding

For the record, Cassie has been happily married for over 20 years and has two amazing sons, so there has never been any sort of romantic component to our friendship. In fact, her husband Thomas, who I also became good friends with, very much supports our friendship because he really has no idea what she’s dealing with.

Obviously he sees her condition and is supportive as he can be, but in terms of actually understanding how it really feels, it was beyond him completely.

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Complete Understanding

Cassie and I can deal with all the emotional aspects of life with MS because that was always an area Thomas was completely lost talking about.

I think that’s the reality with most friends and family; they try to empathize with us but they really can never fully understand what it feels like (and hopefully they never will). I think this applies to anyone suffering with a debilitating disease — you could certainly say the same about everything from depression, to Alzheimer’s, to Parkinson’s, to fibromyalgia, to cancer.

Cassie and I started out communicating via email and eventually evolved to using MSN messenger — this was the early 90s, remember? We started talking on the phone on occasion, and that quickly developed into talking on the phone daily. We’d talk for hours every morning.

Over the years, our conditions have changed rather dramatically. Cassie has an amazing aggressive neurologist who started her on monthly intravenous immunoglobulin (IVIG) treatments. These treatments not only slowed her progression, they actually turned things around for her. Miraculously (and that’s the only word that even remotely comes close) she has actually managed to regain a huge percentage of her memory capacity.

In the meantime, my MS has been very much affecting my cognitive abilities over the years, and my short-term memory capacity has been massively affected. So now I’m the goldfish (a handle I’ll happily accept after all these years).

13 Years Later

Cassie and I have been incredibly good friends now for approximately 13 years. We have actually only met in person once, about eight years ago when she and her family took a short vacation up to Toronto for a long weekend.

And while we’d never actually met before that, when we did finally meet it was very much like seeing an old friend. It was as though we’d always lived next door to each other, rather than over 500 miles apart.

We don’t talk every day anymore, but we remain close (she essentially has a full-time job volunteering at one of her son’s schools, which 13 years ago seemed beyond impossible). When we do communicate, it’s as it’s always been. Our connection is far beyond anyone else in my life, and I count Cassie as one of my closest friends beyond a shadow of a doubt.

So, to all my brothers and sisters who are dealing with this terrible condition, my advice is simple: seek out a friend with MS, or a support group, or hell — maybe just send an email to a strange Canadian. You just never know.