

Having a Bizarre Time With MS



“Seinfeld” has an episode called “Bizarro Jerry.”

For those unfamiliar with the show, the character Elaine meets three new friends, similar in physical appearance to her closest friends-Jerry, Kramer and George. These doppelgangers look like her best friends but they act completely different. It is as if she has entered a parallel universe, somehow connected, yet completely opposite.

In a way, I have my own **Bizarro World**.

MS is, to put it mildly, quite odd. I’m not exactly sure why or how I developed it and can’t tell you, with any degree of confidence, what my future with MS might be.

Strangest to digest is that so many of my symptoms of MS are **invisible**, resulting in me **appearing** healthy...but I’m not. A regular day for me might include:

- Blurred vision
- Vertigo
- Brain fog
- Extreme fatigue
- Joint pains and body aches
- Spasms
- Noise intolerance
- Loss of balance
- **Foot drop**

Sprinkled in are an endless array of altered sensations throughout my body:

- Tingling
- Crawling
- Burning
- Cold (or wet) hands (or feet)
- Numbness

So, how is my existence with MS is divided into two worlds?

There is my online persona where I openly discuss the unique experience of being a husband and father living with MS. I go into detail about how difficult the journey has been... and the silver linings I've found along the way.

But in real life, I don't want others—my family, friends, or even the casual acquaintance—to know the havoc MS is causing. If you're around me, I want to share smiles and laughter, not create sadness and concern.

If you see me out in the neighborhood, at a party or at one of my children's events, I do my best to only showcase the normal version of me. I keep my **Bizarro** world where I prefer it, off in another dimension.

I grimace through the aches, poke laughter at my stumbles or forgetfulness, and try to ignore or will the odd sensations away.

If someone asks how I'm doing, I deflect or demur as to not give MS any further power; it's already impacted my life enough and taken so much. Most times, I humorously quip that I feel "like a million bucks."

I'm not intentionally trying to deceive people, I just want to give a smooth husband/father/friend/neighbor "experience," unobstructed by the bumpy world of MS.

Some might call it pride or stubbornness. But it's how I cope. I view each instance as a chance for me to cheerfully shove MS back into the other dimension, where it belongs.

But when I'm alone, I enter the other world. In **Bizarro** land, I don't fear telling people I'm in pain, I actually strive to tell the whole, unabridged story. I want people to truly understand the raw and sometimes uncomfortable truth of living with MS.

I do wonder, what would happen if I allowed my two worlds to meet?

When someone asks "How ya feelin?," instead of a silly refrain that changes the subject, I could shed some light on the bizarreness that is MS.

I'd replace "a million bucks" with:

- “Got off to a rough start this morning. My hands were burning and it was as if somebody was sticking needles in them. Later, as I was making coffee for my wife, they felt just like two balloons.”
- “My right leg started dragging behind me again today when we took our dog on a family walk. Sure, the pooch didn’t seem to care but I’m concerned that my kids noticed...and it worries them, or worse they are embarrassed by it.”
- “When my wife was unpacking the groceries today, I had to leave the room when she was putting the eggs away. Certain noises really upset my senses and for some reason.
- Nicked myself shaving this morning. I wasn’t in a rush...it’s just that sometimes I get blurry vision, which doesn’t mix well with holding a sharp blade up to my face.”
- “I’m tired. I mean really tired. The kind of tired where your eye lids hurt to be open. The bizarre thing is, I’ve had quite a relaxing day. But with MS, it feels like no matter how much I might rest, I’m rarely rewarded with any extra energy.”

On “Seinfeld,” Elaine’s **Bizarro** world met her real world and it was not a positive result. The two worlds collided and she realized that she was better staying with her real friends, in her regular world.

I like writing about MS. I want to educate, help people understand this awful disease and connect with others so they know they’re not alone in their fight.

But I also don’t want it to dominate every interaction I have. That’s a gloomy place to be and I prefer to exist in the light, searching for the silver linings, in my bizarre Life Less Traveled.