

My MS journey isn't all bad. Really.



I've gained new lifelong friends and a new appreciation for the good things.

by Steve Feinstein

Oh boy. Something's up. Something's just not right."

This is how my multiple sclerosis journey started. It might sound familiar.



Steve Feinstein with his friend SRG, whom he met online and then in person during a trip in 2022.

I'd been having some physical issues for a few years. The first time I noticed something was off was in January 2011, at age 57. I was in Amsterdam for a trade show. At the end of the

day, we had an off-site meeting and getting a cab was pretty much impossible.

The meeting place was nearby, so we decided to walk. Halfway there, my legs were shot. The bones in my legs had been replaced with rubber. It was Amsterdam, not Boston, where I live, so I couldn't tell them to go ahead, since I had no idea where I was. Somehow, I made it, but I had to sit down and pretend I was reading some notes so no one would suspect anything.

These bad events started happening more often, and I couldn't slough them off as "just one of those things."

I'd tell my primary care physician about my leg fatigue, and he always shrugged it off with, "Work out harder, do more weight-bearing exercises at the gym." Unfortunately, many primary care doctors have little understanding of MS. In 2017, I really put up a fuss.

So he said, "OK, we're sending you to the neurologist."

We did the usual things (stand on one foot with your eyes closed, walk tightrope style, walk fast down the hallway, etc.). He didn't like what he observed and sent me for a full-body MRI.

When the results came back, my neuro said, "You have multiple sclerosis. The myelin covering your nerves...."

I don't think I heard anything after he said the words multiple sclerosis. Like you, right?

Many of us grieve when we realize the "old" us is gone for good. Things we used to take for granted are now impossible. We look at the milk on the other side of the supermarket while we're in the produce section and ask ourselves, "Do we really need milk today?"

When we go out to dinner, we take note of where the bathrooms are and if it's a long walk from our table. So many of us do this. It's our common language.

The upside of MS

However, there is an upside to having MS.

I'll be the first to admit that I'm lucky compared with many others. It's more of a work-around than it is a life-defining disability. To others, I act reasonably normal, and you'd have to know that I have MS in order to recognize the "cheating" and shortcuts I take.

Like with so many things — everything it seems, from hobbies to fan clubs to collectors, you name it — there is an Internet support group for people with MS. I'm on an MS social site, where people with MS from around the world contact others to talk, ask questions and express anxieties.

The nice thing is that people are people, regardless of where they're from, regardless of any disease, regardless of age, color, gender, political stripe or anything else.

We mostly use stage names, not formal names. MoveAhead, Laura67, SRG, LKJ, DaveBaseballGuy.

It doesn't take long before people become really good friends. You know what they do for a living, you know their spouse's name, how many kids they have, everything. You look forward to being in touch with them every day.

These amazing people are now inextricably part of my life. We're open and sharing with each other. We cheer each other's triumphs. We rib each other mercilessly with snarky sarcasm. They are as real as it gets.

The only missing piece of the puzzle was to actually meet in person. But that finally happened last summer for three of us (SRG and Kim). We picked a date, and I hopped on a plane.

Meeting for the first time

Man, it was great. It was like we'd seen each other yesterday combined with the excitement of meeting for the first time. We went to lunch, then afternoon drinks, then dinner. I picked the hottest day of the year — 100° in the city — so walking two blocks from the hotel was a challenge. But guess what? We all have MS! We get it, we understand. I didn't have to "fake it" or pretend. It was just another thing we had in common.

So, to me, MS is not all negative. Sure, there's plenty of that: The leg weakness, the balance issues, the frequent bathroom trips, the end-of-the-day fade, all that fun stuff. We all know those favorites — and more — only too well.

But MS has some definite upsides: A disease like this heightens one's appreciation for the good that you have in life: your family, your community, enjoying simple pleasures without comparing yourself to others. It's refreshing, liberating.

The biggest upside of MS for me has been the universe of new lifelong friendships I've discovered. Some are now in-person friendships like with SRG and Kim, while others will remain virtual forever. But they're all real and every one of them has enriched my life immeasurably.

I couldn't begin to imagine my life without them. Things are good.

Steve Feinstein lives in Foxboro, Massachusetts, with his wife of 33 years. They have two adult daughters and five grandkids. Steve is a retired marketing communications/product development executive and a pretty decent jazz drummer in his spare time.