

MS Tidbits: Pithy Musings on Living with Multiple Sclerosis



I realized the other day that I've had MS for more than half of my life. I was diagnosed when I was 29, in 1991; it's 30 years later. Yikes.

Along the way I've thought a lot about how MS has affected my day-to-day life. I've always been introspective, and I've always enjoyed writing. Hence this blog, which shares some observations on living with MS. Some are humorous, I guess, and some are poignant. Maybe there's even some good, practical advice. In any event, enjoy.

Toilet Paper, Schmoilet Schmaper

Demonstrating once again that few things are all bad or all good, MS has turned out to be a surprising boon in the era of coronavirus. Who would have thought that MS-related chronic constipation could come in handy during a pandemic? Not I.

But it has. While others in my part of the world have been fretting — or worse — over their toilet paper supplies, I've been as chill as the proverbial cucumber. Toilet paper? No problem. I have enough for the next year and maybe beyond. So there, you non-MS people!

As I've always said, there should be **some** perks to having a chronic disease.

No Spring in My Steps, or, T.S. Elliott Was Right

I'm going to whine a little bit. It won't take long, I promise.

So, I rarely begrudge other people their good fortune. You're taking a month off to travel across the country? Fantastic! Have a great time. You got a promotion? Good for you, congrats!

But... in the spring of the year, I can't help but feel a twinge of resentment as I watch people outside celebrating the warmer weather with an almost literal spring in their steps. I certainly feel the same lift in my spirit. However, this doesn't translate into my legs feeling any less lead-filled and clumsy.

My late uncle used to tell the tale of meeting a man in 1960 who was burdened by a colostomy bag. This man told my uncle, "never take a good crap for granted." I feel the same way, especially in April, about long walks.

A Bladder Full of Zen?

I was visiting with my brother at his place the other evening and I announced that I had to take a leak. He said, "OK, I'll see you on Thursday." It was Monday evening.

I often take a very long time to urinate. MS-related bladder spasticity, I'm told. I'm not sure what, if anything, I can do to speed things up. I tried alpha blockers, but they made me feel jittery. No thanks. I've talked with a urologist about Botox injections in my bladder, but I ultimately decided that things weren't bad enough to try that just yet.

What has helped is trying to stop thinking so much about urinating while I'm trying to urinate. Say what? Yeah, this has a distinctly Zen Buddhist, gentle paradoxes feel to it. I strive to achieve a state of relaxed concentration. I think that I first ran into that phrase—relaxed concentration—in the context of (trying to) improve my golf swing back in the day.

But wait. "Strive" is too strong a word, and so is "achieve." It's more a process of letting go (pun intended). It's akin to what hitting coaches in baseball call "trying easier," when they're helping a player who's struggling a lot at the plate, get the heck out of his or her own head. Easier said than done in baseball. And in the bathroom as it turns out.

Helpful hint: Put the smartphone down and think of flowing, frigid rivers. But don't think too much....

The Sweet Kindnesses of Strangers

I am ecstatic to report that kindness is everywhere in my experience. Thus, among other things, people hold doors for me all of the time; they throw away my trash at pizza joints after I've finished eating and am struggling to get my things together; they often surrender their seat on the subway (but not always, because so many of them are in that subway-riding zone and not looking at anyone else); and they put my dumbbells away at the gym.

How cool is this stuff? Fills me with hope and makes me teary when I think about it, which I do often because it happens a lot.

I think it helps that I walk around using a crutch. The psychosocial types would explain this in terms of the salutary effects of conspicuous disability. Whatever. I just know that it's really common and so heartwarming. Again, few things are all bad or all good it would seem.