

Back to Square One



“Just when I thought I was out, they pull me back in!”

Anyone who has seen the classic Godfather trilogy remembers this iconic line from Michael Corleone in the final chapter of the saga. Unfortunately, this was the one good line in a pretty disappointing movie. Or, at least we can all agree that the third one wasn't as good as the first two. Another thing we certainly can agree on is that 2020 feels like we are all in a bad movie. And, as a person living with multiple sclerosis in this bad movie, I can totally relate to Michael Corleone's line.

I thought I was done having to tell people I had MS. I thought I was done having to explain that although you can't see it, I have a disease. I thought I was done telling people that I go into the hospital 4 times a year to be infused with Rituxan, an immune suppressing drug to slow the progression of this disease. And then, hello COVID-19.

Turns out, Rituxan may be linked to an increased chance of being admitted to the hospital or needing more intensive care treatment due to COVID-19.

When you are first diagnosed with MS, it feels like trying to take a sip of water from a fire hydrant. All of us are different. No two people with MS experience the same symptoms, take the same medications or face the exact same struggles. One thing we do all share is that eventually, you need to let people know. There are going to be appointments to go to, changes in habits, work accommodations, adjustments to weather, and the list goes on and on.

Every person with MS has a different level of comfort in how they want to let people know, but it is common sense that eventually, you are going to ask for some help and understanding. And like with a lot of things with MS, this isn't always easy. Quite frankly, talking to people about my MS is exhausting. It is hard to explain, and although most people are supportive, understanding and loving, it still takes a toll to talk about all of these strange factors that affect your body.

Oh, and then there are the comments. My goodness, the comments. All my friends with MS are laughing right now while reading this. If I had a nickel for every person that told me, "hey, I heard about this diet that cures MS," or "I know a person with MS, do you want to meet them?" And, my favorite "I **knew** a person who **had MS**." Think about that. There isn't a cure. Soooo... anyway, let's do what I usually do. Change the subject.

We all go through this, and we get to a point where we move forward. There is a sense of victory when you have your routine down, you have your support system, and you are able to finally focus on living with MS.

COVID-19 forced all of us to go back in time. I find myself having to explain to new co-workers why I am not ready to sit in a meeting, inside with people I don't know. I have to tell new friends why I'm still not comfortable getting together like we used to, even as we start to open back up. I have to tell complete strangers to please keep their distance and wear a mask. And every time I say it, I see that look in their eyes that I used to see when I was newly diagnosed. That look says to me, "But you look fine. I don't understand."

Well, here we go. Let me explain. Just like the beginning, most people are great about it, but those comments still get you. The toll of dozens of these conversations a week sets in and I find myself wanting to yell at COVID-19: "Just when I thought I was out, you pulled me back in!"

Spoiler alert. Michael survives and fights to the end. So will this Michael — thanks to the incredible support of my loving family, friends, doctors and amazing people at the National Multiple Sclerosis Society. My final movie has a long way to go before it's finished, and I promise you it's going to get better reviews than Godfather 3.

Editor's Note: The Society continues to be there for people affected by MS. The recommendations referred below reflect the information available during the time of this blog's publication.

For the latest information and resources related to COVID-19, please visit the Society's [Coronavirus Resources Page](#). Find additional resources through our [Ask an MS Expert webinar series](#).

The National Multiple Sclerosis Society is proud to be a source of information on multiple sclerosis related topics. Unless otherwise indicated, the information provided is based on professional advice, published experience, and expert opinion. However, the information does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.