

I've Got This:  
Navigating life, multiple sclerosis and COVID 19

by  
Mike Knight

It was an icy late December morning in 2013. My wife, Michelle, and I were on our way to an appointment with my neurologist. After six months of waiting, today we would find out what caused my right foot and leg to temporarily quit working the summer before.

Twice.

I wrestled with the car in silence, trying to keep it — and myself — under control as we skated down the street. I was 53-years old at the time.

The appointment and diagnosis followed a battery of CAT scans and MRIs, nerve and optical evaluations, bloodwork and a spinal tap prompted by those two inexplicable...incidences.

A few minutes after checking in we were led to a small exam room. My neurologist, Dr. Davidson (not his real name), tapped on the door and after entering, introduced himself to Michelle, then dropped a stack of x-rays clutched in his hand, scattering them across the floor as he bent down to collect them.

Dr. Davidson told us the tests indicated I had multiple sclerosis (MS), a frequently disabling disease of the autoimmune and central nervous systems affecting an estimated 1 million people in the United States each year. Its cause was unknown, he said, and while drugs existed to slow the disease, it was incurable. Not everyone became seriously disabled by the disease, he said, but some did.

Only time would tell if I was to become one of them.

Suddenly the small room became a closet and our eyes danced to avoid each other's glances. Finally Dr. Davidson asked us if we had any questions. We asked him what would come next with the disease, and how to prepare for it. He noted that I was in good shape and seemingly in good spirits, which was...*good*...though really, when are those attributes ever deemed bad?

As for the progression of the disease and preparing for it? Everyone's experience with MS is different, he said, making future outcomes impossible to predict. Which meant it was similarly impossible to prepare for too.

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The Mystery of MS

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There is no single "aha!" symptom that screams "You've got MS!". Instead, it's often a host of issues that at first glance seem unrelated from one another, punctuated by an event that demands exhaustive testing — and specifically, a spinal tap. My temporarily paralyzed foot episodes were just such a punctuation, and a number of weird maladies became so much easier to understand.

In 1994, Michelle and I took a trip to Jamaica over the Christmas holiday and upon returning home, I began to experience tingling in my right hand. I went to my doctor to get it checked out. After a cursory examination she told me she couldn't find anything wrong with me, saying that if the tingling went away, not to worry about it. It did and I forgot about it.

But MS also "shares" symptoms with more common illnesses and diseases which makes detection harder still. Its relapse-remit component complicates matters further and it isn't uncommon for a diagnosis to take decades.

Over the next 19 years that incident was followed by double vision while playing tennis (explaining volumes about my game), a bulging right eye, burning in the soles of my feet, gait problems when I ran and occasionally dropping things.

Some of those issues came and went. Some were misdiagnosed and after multiple doctors' visits that went nowhere, I learned to live with them.

In many ways, MS settles into the body like a virus settles into a computer, lurking in the background, screwing things up, slowing things down, until one day you try to launch Excel® and you can't lift your foot off the ground. You reboot, it goes away and then a few weeks (or months or years later), it comes back.

Maybe.

According to the Cleveland Clinic, “Multiple Sclerosis is thought to be an autoimmune disease in which the body's own immune system mistakenly attacks normal tissues of the body. In MS, these attacks are aimed at the myelin in the Central Nervous System (CNS).”

Myelin acts like “insulation” covering our nerves; the attacks against it can leave multiple scars (sclerosis) on it, disrupting communication between the brain and the 650 muscles we need to function properly every day. That disruption causes muscle weakness, problems walking, tremors, bowel and bladder issues, poor coordination and extreme stiffness.

But wait, there’s more.

People with MS often experience nerve pain, itching, cognitive and emotional changes and perhaps not surprisingly, depression.

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Aftermath

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I “retired” in 2016, receiving long-term disability benefits along with Social Security Disability Income. Michelle continues to work full-time; like most people, we need the income. We also need the healthcare insurance; the two MS-specific drugs I take list for \$120,000 before insurance and co-pay assistance programs kick in.

My dominant hand’s functionality is such that I can no longer type or write by hand and must now use voice to text technology to write anything more than my name. Michelle must now cut my food and help me get dressed each day.

I use a walker to get around upstairs but spend much of my time in a wheelchair downstairs or when we go out. Traversing our nearly 100-year old home — with its multiple flights of stairs — is a workout. Our home has two bathrooms, one upstairs and one in the basement. Consequently, I generally live upstairs, making one trip downstairs and back to hang out with Michelle and have dinner together at night.

The physical manifestations of MS are hard. The emotional ones are harder. Michelle and I have been married since 1986. It’s torture watching her do everything – cook, clean, run errands, the list is painfully long. Many of the things we enjoyed prior to MS, camping or biking

or playing tennis, going to catch a band we liked or out to dinner, last-minute trips to Nashville for the weekend – either long gone or terrifically hard to do.

I've learned MS can be a chaotic and humbling disease bent on painting those who have it into ever-smaller corners. Living with it and being largely confined to two rooms in our home feels a little like being in prison (a very nice one, but prison nonetheless).

At the beginning of the COVID 19 pandemic I ran across multiple articles written by former prisoners detailing how they survived life in confinement. Most focused on their ability to adapt, maintain a routine, learning to live with far less, staying connected and focusing on what they do have, not what they do not.

They could have easily been writing about living with MS. Some days are far easier and more successful than others of course, but largely we continue to live our lives trying very hard to recognize and relish every victory and quiet beautiful moment, no matter how small. We continue to make each other laugh, sometimes so hard we cry.

As hard as it is, we try not to live in the past, or even the future really, only the present, and try to keep our expectations in check. We are also extraordinarily fortunate to have a small circle of dear friends and loved ones who try very hard to make our lives easier and poke and nudge us if we fall silent.

I continue to write two or three articles a year, largely for the National Multiple Sclerosis Society, and many of my former colleagues check in to see how I'm doing.

My life during the pandemic isn't too different than it was before. Prior to the pandemic we had finally gotten comfortable going to restaurants with me in my chair, and I miss being able to do that. Still, I'm used to giving things up, and this one will likely come back once we get a handle on managing the virus.

Unfortunately, in early 2019 I developed MS-related breathing issues and developed pneumonia. While having MS doesn't increase the likelihood of me contracting the virus, it does increase the likelihood of struggling if I do. That development, along with varying degrees of mask wearing and social distancing where we live has indirectly painted me – and us – into a smaller corner yet.

At least momentarily. It's possible that we will return to some of what we once thought was normal. It's possible that we won't. I'm not worried about it either way. Because I've got this. And I know how to make the most of every moment while I do.