Adjusting to Life With Late Onset MS

by DEBRA ROBERT

On the Cusp of Late Onset MS

Two years ago I was at the peak of my career, loving every minute of it and making a tidy buck as well. I'd worked hard for decades and had earned my place in the world. At 46, I was both respected and in-demand.

I was a tough independent world traveler. Life was not perfect, but it was fulfilling and exciting. In the throes of that very busy year, I experienced a few rather alarming mental and physical oddities at times, but I shunned them away. Nothing was going to keep me down.

Nothing, except while in the midst of working a 95-hour week, a hemifacial spasm (an involuntary contraction of the facial muscles on one side of my face) steadily overtook my attention and concentration. The spasm was painful and frightening, ripping me away from the work I had to complete.

My face crunched up so badly it closed my right eye. I could not put this strange happening on the back burner. Looking like Popeye the Sailor, my doctor sent me to the emergency room, thinking I was having a stroke. That was the day the ER doctor walked in and everything changed. He stated plainly, "You have a large brain lesion that must be looked at immediately, it indicates multiple sclerosis (MS)."

Wait a minute. I'm pushing 47, I have shows to fly to, clients to wine and dine, I've got deadlines on torn apart projects only I know how to complete. This is ridiculous. This makes no sense. Wasn't MS something you got a lot younger? It took another eight months to be officially diagnosed on Christmas Eve, 2014.

Denial and Reality

By May, I'd lost my job after having worked 25 years in live event and concert production. This is a tough career track to break into and even tougher to stay on top of your game.

I'd made it and I loved it; the challenge of pulling off live shows in front of massive audiences, traveling alone all over the world to meet up with the crew — it was exciting and demanding. One had to be rock solid and unshakeable in very stressful situations. Grace under pressure, and no room for error or indecision — that's what drove my days.

Error and indecision did creep in when I tried to get back into freelancing, praying I was not at career's end. I figured if I rested up enough before a gig, I could make it through.

I was kidding myself, unable to respond to so many people hovering over my shoulder while running the graphic content for who was onstage. My hand tremors and numbness from sitting made the days seem like endless stints in hell.

I had lost my edge and I could not fake my way through it. If my inability to keep up would tank a show I could

potentially ruin other people's careers. This was my worst nightmare and I had to admit my show days were over.

All of a sudden, everyone I knew had a story about someone they knew with MS. The droves of well-meaning tales did not seem to have anything to do with my life.

One similarity in all the stories did get to me; everyone seemed to have gotten MS much younger than I had. It became tiring to hear about how everyone's friends or relatives had adapted so well to MS and were able to find or begin careers that worked around their symptoms and mobility woes. None of this was helpful for me to hear.

I knew, in my career, there would be no way to accomplish this. I felt isolated and alone. Confusion and fear took over my days.

Next page: learning more about LOMS.

Learning About LOMS

I began digging into research papers online, looking at different types of MS, mortality rates, symptoms and the like. I soon discovered the phrase, late onset MS (LOMS). This population is diagnosed with MS later in life, over 50 years old as compared to the average diagnosis, which was closer to 30 years of age.

No, I was not in the age bracket for LOMS, but I felt a certain kinship with this group. Had I not had such a harsh outbreak when I did, who knows when I may have sought the right kind of help.

It turns out, late-onset MS can mimic completely normal signs of aging, like memory issues, menopause symptoms, diminished eyesight and lessened mobility. I related to this because I realized I had to push my mind and body more and more on show-site and in daily life.

Diagnosis Can Be Tricky

In order to stay on top of what was my career, I had to maintain the level of stamina equal to those 20 years my junior. I had this down cold and never missed a beat

Looking back, I felt the changes in my body but I chalked them up to bouts of show-exhaustion, something that usually doesn't hit until the plane ride home. I hid my symptoms from everyone, including myself.

LOMS can be difficult to diagnose because symptoms can mimic those of other, often serious, neurological conditions that become more common with age, such as memory issues and stroke.

Compound these factors with the supposition that many who are diagnosed later in life were possibly like me, ignoring early signs and symptoms, shooing them away because life was too busy.

Might a MS diagnosis come much later in life for some, detected only because of a severe outbreak or symptom?

If I hadn't finally listened to my body and got the medical attention it demanded, might my MS have remained under the surface for a few more years? If so, might I have been designated a LOMS'er possibly with a more accelerated pace of the disease?

More Questions and Ponderings

There is not much out there in terms of data for the layman that explains or defines much of what we want to know. I did discover that for LOMS'ers, a primary-progressive disease course is a more frequent diagnosis than in the younger MS population usually living with relapsing-remitting MS for years before possibly moving to more advanced stages.

Consider an individual who had MS for years but went undetected until they were past 50. Would this mean that individual would technically be diagnosed with LOMS? Another question, might the accelerated pace of MS at this demographic be because of aging itself?

Answers to these questions, for it may lead to individuals in similar situations to mine to not ignore potential health threats. Also the more we understand our disease, regardless of age, the better we can make relevant choices and plan for out futures.

Not so Old, Not so Young

Mortality has been on my mind a lot lately. How could it not when I was just starting to find balance in my life. I have no children; I identified myself through what I did for a living.

I didn't get to retire gracefully when I was ready. I was shot out of my own life like a flaming cannonball that lands in a barren field, a dud. More importantly, I was (and am) a newlywed, insanely in love for the first time.

I'd entered into a marriage with tremendously good health and a great income. Just months after our wedding, I was hospitalized on our first Valentine's Day with paralyzed intestines.

It's hard enough to carve out a fulfilling and patient marriage, having had full lives beforehand. It's a constant negotiation and recognition of each other's patterns and buttons. Now I have all new patterns and buttons, and this old dog must learn new tricks.

I think about those with LOMS, and how disruptive it must be to find out in your golden years that your entire way of living must change. They say aging isn't for wimps; I'd love to hear from those with LOMS, I bet they can teach us young ones how to make this look good. I, for one, intend to forge this new reality into a fulfilling path, MS and all.