My MFS/CIDP Journey

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According to several articles I have read about Miller Fisher Syndrome the prognosis for recovery is excellent with most patients making a full recovery within a few weeks or a few months. And then there is my experience...

I am a Prairie girl born on March 13, 1919 in Saskatchewan where I lived for 81 years. I graduated as a registered nurse in 1941 from Regina Gray Nuns' Hospital and served as a Nursing Sister in the Royal Canadian Medical Core during World War Two. I continued with my nursing career after my marriage until I retired at the age of 58. In 2000, I moved to British Columbia to be closer to my two sons and their families. I began having a few health problems such as two TIA's in 1999 and a bit of a heart problem. In September of 2007, I made a decision to move to a Seniors' Residence (an old folks home). It offered independent living and also a care wing. I was still active in the community as a member of Eastern Star and involved in several bridge groups, often playing eight times a week. I was still driving and even made a few trips back to Saskatchewan driving by myself.

Suddenly at the end of January of 2008, my right eye (lower lid) became incredibly painful. My daughter-in-law said I had two little white spots on my lower lid. I immediately went to see a doctor and was given eye drops for an eye infection.

The next morning, I had pustules on my right eyebrow. My first thought was shingles, so I went back to the doctor who now prescribed an antiviral medication. But it was too late and I had developed a very severe case of shingles. Was this misdiagnosis because of ageism? I wondered. I was 89 years old.

And so began my life changing journey with this MFS and later CIDP. I also developed a severe case of thrush in my mouth and throat; which I believed was causing difficulty in my swallowing and talking. With the help of a care aid, I was determined to remain in my suite. I became very weak, and after having several falls and when I could no longer speak and swallow, I decided I had to go to the hospital. This was in the middle of February.

The doctor in the emergency room kept examining my face and throat and finally said, "It's not the thrush, it's not the shingles, she's paralyzed!" After a series of MRIs, scans and blood work, I was diagnosed with Miller Fisher Syndrome. The only treatment I was given was a course of prednisone. There was no mention of an IVIG treatment. I had no physiotherapy, and no explanation about my condition and how severe it was. I had no follow up after my initial treatment and was told that I would be fine in just a few months. I was put on a diet of thickened liquids gradually moving on to a puréed diet. The paralysis progressed down my body to my legs and feet also paralyzing my bladder so I had a Foley catheter for quite a long time. My bowels also became paralyzed, and to this day they have not fully recovered. As a result, I take a cocktail of laxatives every night. A couple of episodes of impacted stool have kept me vigilant.

While I was at the hospital I was taken to the gym on a regular basis and was assisted by two staff members to learn to walk again. I remained in the hospital till the 30th of March when I was discharged and returned to the care wing at my seniors' residence where I remained until the end of May. Then I was able to return to my own suite requiring the help of a care aid for a couple of months. I almost wore out the carpet in the hallways with my walker trying to continue walking to regain my strength. I gradually improved to the point where I was able to attend bridge tournaments at Harrison Hot Springs and with other groups closer to my home. I was able to travel to Palm Desert spending quality time with family there as well as on the lower mainland. I became very active in the community within the residence becoming the President of the Resident Council, which was formed in late 2009. (I remained president of the council until 2016). I also organized a bridge club and a knitting group. Our project for the moment is knitting sweaters and caps for babies in Rwanda. I received a Provincial Award in 2014 from the Simon Fraser University Gerontology Research Centre. This was a senior's leadership award for service to seniors in the community.

During this period I was dealing with residual issues. My right eye continued to be troublesome resulting in many visits to the ophthalmologist and requiring steroid drops. Until a year ago I saw my dentist every three months for cleaning to help keep my gums healthy. I have found that stress will trigger a relapse.

In June of 2013 my oldest son died unexpectedly of a heart attack. My close-knit family was devastated. As the only senior family member left, I needed to be strong. This has been a very difficult time and still is, but we do learn to live again. With every tear we shed, we learn.

By the end of 2013, I became very ill. It is very hard to describe, but I had a general feeling of malaise; I had no appetite; I lost weight; I was weak and tired. Also, I had more trouble with my gums and more shingle pain above my right eye. At this time, I was taking a blood thinner as a precaution after having two TIAs back in 1999. Because of this the capillaries around my lower legs and ankles would continually break down and bleed, resulting in blood under the skin. The skin on both legs broke down resulting in open areas. These had to be dressed and cared for by my care-aid. They took many months to heal.

I had some trouble walking and speaking and swallowing and was put back on a prednisone regime. I continued to go to the dining room using my power wheelchair and continued to partake in some activities. In the fall of 2014, I attended the GBS/CDIP conference with my daughter- in -law. In the question period I asked, "Could one have a relapse of Miller Fisher Syndrome?" I was told, "Yes, you can even 5, 10, or 15 years later."

My GP made a referral for me to see a neurologist. My appointment was on May 20th, 2015. During our discussion, I was told they did not expect me to leave the hospital back in 2008. Why was I not told? Why was my family not told? Then to my great surprise I was told I now have CIDP. To say the least, I was shocked, we both

were. There was no mention of a follow up or help with any of my activities. Since then, I have had two episodes of shingles controlled by the antiviral medication which I now take every day. I still have trouble walking and my walker is never far from my side.

My health improved and remains fairly stable. In October, my daughter-in-law and I attended an information afternoon regarding GBS and CIDP. I have attended all these meetings since 2008 and have found them of great value. Generally, the age range for these conditions is from 8 months to 81 years. I guess I changed that. I was 89 when I was first diagnosed. The liaisons for the Foundation in BC, Suzan Jennings and Sherry Nejedly, have been a great help to me. In addition, I have enjoyed many visits with Gail Kammer in Saskatchewan.

As a result of this meeting, a referral has been made for me to see Dr. Kristine Chapman, who is the director of The Vancouver Hospital Neuromuscular Disease Unit. I am looking forward to my visit with Dr. Chapman. At the moment I am back on prednisone. I think this relapse was caused by stress after having a hernia repair.

In the many stories of GBS and CIDP that I have read there is a common thread of determination that this disease will not define our lives. This is not who we are or what we are. We are a group of people with this strange disease that changes on a whim. Without the loving and caring support of family, friends and the wonderful support of the staff at my residence, this journey would have been much harder. It has not been easy and it is not over; however, being an avid bridge player, I have learned that in life as in bridge we play the hand we are dealt. I am now looking forward to celebrating my 98th birthday.