

My GBS Journey (Acute Peripheral Axonal Polyneuropathy)

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Originally Published 2019 March Newsletter

In the winter of 2004/2005, I paid a visit to my GP for some routine item. During the visit he asked me if I had had the flu shot for that winter. I told him "No" and I didn't want it. I had never had the flu shot and had resisted it, remembering the tragic aftermath of the Swine Flu immunizations of the '70s. However, he pressed me and I said, "Will I get sick from it?" He said "No". So, I gave in. I never thought more about it until several months later.

In June of 2005 I was driving back to Ontario from Florida when the ill feeling I had had at the start of the trip caused me to stop at a hospital off the 195 to see what was wrong. To cut a long story short I had developed cellulitis in my upper right chest from an infection received from an injection in Florida for a sore shoulder. I called my husband who flew down to Charleston to drive me back to our Ontario home.

As instructed by the US hospital doctor I immediately saw my own doctor who sent me to our local hospital where I was admitted. An operation followed and the cellulitis treated and I was sent home with a PICC (Peripherally Inserted Central Catheter) line to feed me constant antibiotics. (Whilst in the hospital I was diagnosed with the superbug MRSA, which turned out to be a blessing for me in subsequent months.) During the two weeks following my discharge from the hospital I began to feel ill again and so desperately tired I could not keep awake while I was sitting in the waiting room at the hospital. The doctor who saw me sent me to the Emergency area of the hospital so that I could be admitted again.

After several hours of waiting for a bed, I was placed in a makeshift area until a more permanent spot could be found. During these waiting hours I developed significant back pain and was only allowed over-the-counter painkillers. At some point someone decided I should have a spinal tap and according to the results the protein level was high - which is, apparently, a possible indication of Guillain-Barre Syndrome (GBS). Incredibly, there never seemed to be a follow-up on these results. The following morning my husband noticed that I had developed a rash all over my body that was presumably caused by the medication administered for the spinal tap. This would be the first of many occasions when I experienced serious reactions to medications I was given.

The next week or so was a blur of pain, medications and confusion. I remember being told to get up to have a shower. No problem, really, except when I stood up from the shower bench to get back to the bed my legs crumpled under me and a male nurse was called to get me up off the floor.

Days went by, mostly with excruciating pain in my legs, then periods of nothing after a pain medication was administered. One terrible night I called my husband, or someone called him for me, because I was literally screaming with pain and nurses would not come to help me. When my husband arrived, the nurses sat stubbornly at their station ignoring his pleas to call a doctor. Eventually, after the other patients added their pleas to my husband's, a doctor arrived. The doctor had the nerve to say that I only complained of pain because he - my husband - was there. My husband was outraged and told him that he was only there BECAUSE of the pain. In many other accounts of a GBS experience I do not see the mention of the terrible pain it can cause. Perhaps others have been treated more humanely. In my case, the doctors finally prescribed sufficient

medication to keep the pain under control but the nurses refused to acknowledge that they were misreading the doctors' instructions which would have allowed me booster shots as frequently as every 3 hours instead of once every twelve hours. The medications I was being given were taking away my appetite and I was eating very little. On one occasion one nurse threatened me by saying, "If you don't eat up your food you will not get your pain medication".

During these early weeks I was in a fog of pain and confusion but I do remember being seen most mornings by a different team of doctors and interns and I became known as the mystery woman. After the fall in the shower, I was run through what I called the "conveyor belt of torture" to have a catheter inserted, and various other painful things that I was not able to remember. Afterwards, I did say bleakly to my poor husband, "Why did you let them do that to me?"

Over the next three weeks the paralysis crept down from my waist to my toes then up my body into my face. At this point, no one had even indicated to me, or my family, any guess at a diagnosis, despite the strong indication of GBS from the spinal tap. From the hospital notes I read that I was suspected of having Lyme disease, West Nile Virus, encephalitis and vasculitis (I have a scar on my ankle where a sample of possibly a vein was taken).

Weeks later, even after the neurologist had diagnosed GBS, another doctor came to me saying that he needed to do tests to see if I had lymphoma. My husband was furious with the doctor for not discussing it with him first rather than upsetting me when I was alone without a family member present. Furthermore, the system did not provide any continuity of doctors who saw me and each team of doctors wanted to develop its own theories of what was wrong with me. It seemed that I was an object of education and curiosity rather than a patient who needed to be helped.

When the paralysis moved to my face I began to panic, thinking that my brain was going to be affected. However, I read in the hospital notes which I paid to get after discharge that, "the patient asked to see a neurologist"!!!! I find it incredible that weeks after the paralysis had started no doctor had thought to bring in a neurologist. Paralysis -> muscles -> nerves = neurologist!!! Was it so difficult to connect the dots?

(As a laughable side note, I read one of the nurse's comments around the time that I was almost totally paralyzed which said that the patient is "a very dependent person".)

After my request to see a neurologist she arrived, gave my arms and legs a few taps, flipped open a book she was carrying and said. "Well, the bad news is you've got Guillain-Barre Syndrome, and the good news is that most people recover from it." My husband was so happy because now we had a diagnosis and therefore, we could start appropriate treatment. The dithering of the other doctors during those early weeks lost precious time. I am permanently impaired because of it.

IVIG (intravenous immunoglobulin) treatment was started and we hoped I was on my way to getting better. This was not to be. The attending doctor reported to my husband that my kidneys were failing. My worried husband did some online research on IVIG treatments and found reports that they can cause renal failure in some patients. He ordered the doctor to stop the IVIG treatments - although more transfusions are usually recommended. A rather heated discussion took place between my husband and the doctor who denied that the transfusions were a cause of my kidney failure. The following day my husband took a report in to him on the subject and the doctor admitted that my husband was probably right so the IVIG treatment was not continued after the fourth transfusion. My kidney problem was resolved.

Following the IVIG transfusions I began to lapse into periods of unconsciousness from which I could not be awakened. My husband was usually the person who alerted the staff on this, or in some cases the Personal Service Worker that my husband had hired to be an extra person to look out for me in

the hospital, seeing that on so many occasions I was not being taken care of properly. Possibly for this reason, and because my breathing test results were poor, it was decided that I needed to go on a respirator. I remember having a feeding tube pushed up my nose and being told to swallow the tube down into my stomach. After that.... nothing. I was put into a medically induced coma, which my husband tells me was for about 10 days. At this point I was in ICU and this would be the first of three occasions when I would be rushed into ICU for having had a critical drop in blood pressure.

When I came off the respirator and was conscious again, I was unable to speak. I wanted to tell my husband that the nurse wasn't giving me my pain medication. I tried to write it down but all I could manage was a meaningless dribble of ink across the page. Then we tried for him to go through the letters of the alphabet and I would nod when he got to the letter I wanted. I got as far as "she won't..." and my husband gave up because it was so frustrating for both of us.

At this point I should relate that my husband, who runs his own IT company, was spending many hours with me and was often having me call him in the middle of the night because of pain. On top of this the doctors and nurses were not helping, particularly one doctor who displayed an arrogant attitude even though he seemed to know very little about GBS. The doctors seemed to be reluctant to hand me over to the care of the neurologist - who did know her stuff, so I never was (in this hospital) in the constant care of a specialist nor, as far as I am aware, did she ever attend me again.

However, after the period on the respirator, I was visited by another group of doctors called "The Pain Management Team". Finally, I thought, someone realized that my PAIN was significant. However, I would have been more reassured if they had called themselves, "The Pain Elimination Team".

Over these early months, at significant cost to my husband, I was attended to by a series of personal care workers, some better trained than others. One in particular, I was so grateful to. She would spend lots of time patiently rearranging the many foam supports around my body trying to get me into a comfortable position. She was like a sister to me and we talked a lot about her life in Iran before she came to Canada. She came on the night shift and I so looked forward to her arrival each evening.

After the IVIG and the Respirator episode and about two months into my stay in hospital I began to recover the use of my arms. To this day I still have two numb fingers in my left hand. I was able to haul myself further up the bed by hanging onto an overhead bar, but my lower half was still completely paralyzed. I was made to get into a bedside chair and table to take lunch but the effort to sit up was overwhelming and after a while I pleaded to be able to get back into bed. Toiletries were an ordeal, enemas, intimate personal care by a stranger, showers lying prostrate on some sort of platform, waiting in wheelchairs in uncomfortable corridors for CT Scans, ECGs, X-rays, MRIs and every other type of test you could think of. One doctor reminded my husband and me that the hospital had spent \$25,000 on tests the previous night. Other tests, like nerve conduction tests were carried out. These were painful and when I was asked if I wanted to submit to another of these tests - which were informational only for the doctors and would not affect treatment- I declined.

Around the third month of my hospitalization, which was September 2005, I was encouraged to start physiotherapy. This was awkward and somewhat embarrassing while still encumbered with a catheter. I felt I was being pushed too hard and got the impression that the hospital was impatient with my lack of progress. I expect I was hurting their bottom line. (A great benefit of the Canadian medical system is that there were no extra out-of-pocket expenses because of my hospital stay and treatment. However, I felt the budgetary pressure.) On one occasion the physiotherapists were telling me to practice sitting on the edge of the bed and to lean down to pick up a bottle on the floor. The bed was high - my feet were not touching the floor - I knew I could not do it and that I would fall and I didn't trust them to catch me before I hit the floor. I suspect that even able-bodied people would not

be able to do this. I realized that I would have to put my foot down - figuratively speaking - and insist that they stop pressuring me. However, I was able to manoeuvre myself with the wheelchair they brought me so I welcomed the bit of freedom it gave to me to get around the hospital with the help of my "sitters". I remember, in the wheelchair, experiencing how cold my legs were and I needed a blanket to keep them comfortable. I still have cold legs from residual nerve damage.

I have mentioned the need for medications. I was taking about 10 capsules/pills in the morning and less than that during the day. On many occasions I was hallucinating or completely knocked out. When I was woken up, I was always asked where I was. Sometimes I was in Bangkok, sometimes New Zealand, and sometimes Arizona, whatever. I talked nonsense with my family and apparently with the nurses, too, since they commented on it in their notes. I believed that my daughter had a close relationship with the nursemaid to Prince Charles.....really? ... and had special invitations because of it. When my son and daughter came to visit me, I believed that my husband had flown them to Bangkok to visit me and

I chatted with them about it. I believed that I could see palm trees and a swimming pool from my hospital window and that white-coated waiters were serving hors d'oeuvres in the corridor. On another occasion I talked to the ICU nurse about the cats that were running around the walls and the one that was poking its head out of the paper dispenser.

At one point, when doctors were trying to drain my gall bladder, I asked for a lawyer because I thought I was going to die. In fact, at a time when I was in considerable pain, I asked my husband to do something to end my life. Fortunately, he ignored me. Whether or not this had anything to do with it or not I don't know but a priest, vicar or other church-related person came to see me. I'm afraid I must not have given him a lot of attention because he never appeared again.

Towards the end of September, I heard that I was to be moved to a different hospital. The rumor was that this was a palliative care institution and we were somewhat scared about this development. However, it turned out that only one floor of this new hospital was for palliative care and the rest was for rehabilitation.

My first room in the new hospital was shared with a patient who either had mental problems or was reacting to medications because she shouted, screamed and threw things around the room. Fortunately, the staff soon learned that I had MRSA and I was moved to a large private room at the end of the corridor. (I never experienced any symptoms from MRSA but it was probably why I was on the strongest antibiotic available to fight it. It was uncomfortable for my visitors since they had to wear gowns and masks, which made them overheated.)

What a relief this move was. The nurses, in general, were KIND. I still had problems with pain and it seems that their routine cannot be broken so, being at the end of their evening medication run, I was often in pain for up to five hours before they got to me. However, the gym was well equipped and the physiotherapists very good. But each time they tried to get me to stand up my legs would crumble under me. My lack of progress was attributed by some to be my laziness!!!! I was pressed to get rid of my sitters, which I refused to do. In both hospitals there was a lot of hostility by some of the staff to me and to the sitters themselves and more than once I was questioned as to why I had them. In one instance, I asked the physiotherapist why I should get rid of them and I was told that it cost us, me and my husband, a lot of money. What a strange answer! I said that surely the expense to us was solely our affair and not that of the hospital staff. I never did understand their position. Perhaps, they saw it as a comment on their care.

In this second hospital I was attended by a neurologist - at last. I believe I had new medications and one was for nerve pain that made my hair fall out in clumps. I was continually searching my hospital gown for stray hairs that were making me itch. One day a sign-up sheet was circulated for the flu

shot. I thought I had better sign up for it since I was in a place with lots of sick people. So, I put my name on the list. A few hours later my neurologist came by to tell me I should not have the flu shot. It was only then that I made the connection with the first flu shot I had ever had some months previously and the GBS that I now had. I caught up with her - not literally - and told her about having had my first flu shot in the months previously and she said there was no connection since it was so long ago. Later, after discharge, I found a study report that said that there was a statistically significant increase in the incidence of GBS within 40 weeks of having the flu shot. She commented that she did not know this. Needless to say, I have never had another flu shot.

Getting dressed and ready for various activities was hard work. The 6-foot tall, muscular head nurse would sometimes help out. She would get my pants on me part way up my legs while I was sitting in the wheelchair, haul me up by my pants' waistband to lean against her large frame, and shake me into them like a pillow into a pillowcase. We had a few laughs over that.

During this time, I was attending sessions with the psychologist, occupational therapist and physiotherapists. After certain activities I had to do I started experiencing nausea and vomiting. I came to relate this to stress. There was a kitchen in the hospital set up on one of the floors so that rehabilitating patients could practice making themselves meals. During this exercise I threw up twice. Even talking with my doctor about throwing up caused me to throw up. On one occasion, after visiting my home with the occupational therapist to assess my living conditions, I again threw up. The occupational therapist said that we would have to remove the bed that my husband and I slept on and replace it with a hospital bed and a single bed, that the bathroom would have to be remodeled, all doors removed, kitchen modified, etc.. I said, "You sound as if I am never going to get better." No response. Still, I was not convinced that I was not going to get better. However, the shock was to come later.

One day I was informed that there was to be a family meeting. In attendance were my husband, my son, my daughter, my granddaughter, and my neurologist who ran the meeting, the head physiotherapist, the social worker, the occupational therapist and the psychologist.

The only thing I remember from this meeting is my neurologist saying to me, "You are probably never going to walk again".

After that I remember wheeling myself, in tears, as fast as I could to get back to my room. A nurse noticed the state I was in and came after me into my room. I told her what the neurologist had said, and she assured me that many people with GBS had left the hospital on their own two feet. I was greatly comforted. However, my husband and I were shocked and angered that the neurologist had come out with this statement in front of everyone without telling us beforehand. I believe that the psychologist had been a bit surprised by this approach too, because he spent quite a bit of time in a subsequent meeting trying to assess my feelings about hearing this so suddenly.

Time passed through October and November with daily visits to the gym. The therapist started me wearing braces around my ankles and tried to get me to stand up between the parallel bars. After a few days of failures, I managed to pull myself out of the wheelchair, grab the bars and pull to a shaky standing position. Yeah! The therapist felt my thighs and said, - I could sense the relief under her breath - "You are starting to recover." I was elated. I could see out of the hospital windows, now that I was standing. I could see how my top hung so loosely from my shoulders. I lost 51 lbs. during my entire stay. Over the months of November and December I progressed, with assistance, to a slow, staggering walk with one of those push/plonk walkers with the tennis balls on the front (or is it the back?) legs.

In early December I was given a discharge date. It was to be just before Christmas. When the discharge day arrived, the taxi took us to our condo building in the middle of heavy snow. But here I

was to rest, to sleep in my own bed next to my husband with a bag of medications, enough to set up my own pharmacy, it seemed.

Life at home was difficult at first. My husband would make me toast before rushing off to work. I would sit in my wheelchair staring out of the window, too tired to do anything. I couldn't get to the bathroom on my own so I managed to wait until about 4:00pm and I would call him to come and help me. We had equipment so that I could get into the bathtub for showering.

My treatment wasn't over. I was scheduled for twice- weekly appointments with the Rehab Centre for the next two years. I never missed an appointment except for two trips we took to Florida where the exercise of climbing up the 18 stairs of our condo seemed to improve me considerably.

I was fitted out with custom braces because of foot drop and I have never recovered from that. My other residual effect is tiredness that I understand is a common problem for GBS recovering patients.

Six months after discharge I came down with some sort of infection. At this time, I thought it would be advisable to stop the medications I was taking if I was going to take something else for this infection. So, I stopped the painkiller, which was a morphine derivative. As soon as I did this, I developed a cough and was so restless and trembling I could not sleep. On an emergency doctor's advice, I went back on the morphine-based drug. I had become addicted to it. Six months after that I was in Florida on my own and I decided to wean myself off this drug, which I did successfully by gradually reducing the dosage to nil.

How to summarize my experience? It was a nightmare for both my husband and I but we survived. First of all, my greatest gratitude is to my husband who gave me the most care and concern possible while dealing with his business responsibilities. My second is to the nurses of the second rehabilitation hospital and to my sitters, particularly my Iranian sitter, for their comfort and care. My children, of course, I am grateful to for their visits and help and to my family in England and the many friends who either visited or tried to visit me in hospital.

I came to trust the nurses of the rehabilitation hospital, not only for their kindness and humanity and for their experience and honesty with me. Friends have asked me if I am angry about what happened to me. My answer is always "No", but what does anger me is the lack of information given out to patients and the public about the potential serious side effects of medications and inoculations. Providing the information should lead to earlier diagnosis and then better outcomes from GBS would hopefully result.

My life is fairly normal for someone of my age. I can't do some of the things I would have liked but I have recovered more than anyone - except me - expected. I use a walking stick and braces for short distances, a walker and braces for longer distances and neither of those when I am at home. So, I have to say, "Life is good", all things considered.

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