



OUR CIDP JOURNEY - From a Caregiver's Perspective

by Patricia Kent

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My name is Patti Kent. My husband of 25 years has CIDP. When I was first asked to write this, I thought, why me? My story isn't special. I am just the woman behind the man; the taxi driver and the pack mule. Do I have a story? Then Jason pointed out, how much easier it would have been on me and my sanity, if I had someone like me, who had been where I am now, when Jason got sick. I was lucky to have many people who let me cry on their shoulders while I went through the stages of grief and mourned our past life. We found the GBS / CIDP Foundation about a year later. It was reassuring to know we were not alone. In 7 years, I have talked to lots of patients and caregivers who felt the same way I did. Remember, you are not alone. Find someone you can talk to, someone who will sit and listen while you vent.

So here is a little bit about us. We were together for 31 years and had just celebrated our 25th wedding anniversary. It was the spring of 2011 when Jason's health started to decline. Our three amazing children were seventeen, fourteen and ten at the time. Our youngest, that will study nursing in the fall and plans to be a doctor, would come home every day at lunch to make sure he was OK. She made and fed her father his lunch, would help him to the washroom and got him back to where he wanted to be for the afternoon. That is a lot to ask of a little girl of ten.

If we are to be completely honest, his illness started earlier than that. As is typical in a lot of cases, we first noticed something was wrong when he fell early in the spring and hurt himself, this was April. He bought a cane at the drugstore to help steady himself, so what he thought was an injury, could heal. By the end of May, many doctors performed countless tests and the only thing they could determine was that his fasting sugars were a little high. "Diabetes" I thought, I can handle this with diet and exercise. We made the adjustments to our diet but Jason's condition didn't improve. It was the beginning of July when I finally convinced the medical community that something was wrong. By this time, Jason needed 2 canes to walk. The severity of his health issues really hit home when I returned from a two-week trip. Since Jason was still driving at the time, I watched him lift his right leg (with his hand) to move it from the gas to the brake pedal, "Dumbass", immediately I had him pull over and it was the last time he drove. By the end of July, he was using a walker to get around. I started to get really worried that there was some underlying issue that the doctors were missing. I even called Jason's family doctor. I give him credit as he talked to me and tried to alleviate my fears. He suggested I take Jason to emergency, like that was going to happen with my stubborn husband. It wasn't like I didn't try. I cajoled and I cried. Boy, I cried a lot of tears that summer. Part of my problem was the not knowing what was wrong and part of it was that I had already begun the grieving process - the life we dreamed about was about to change dramatically and subconsciously I knew it. By the beginning of September, Jason was confined to a scooter and his weight went down to about 140 pounds. It was the end of September after lots of tests, CT scans, an MRI and appointments that we finally had a diagnosis of CIDP. Jason started his first of 110 Intravenous Gama Goblin (IVIg) treatments that October. By the beginning of December, we realized that he needed to focus on his health and was no longer able to work.

This illness changed our household dynamic. As I not only became, the primary bread winner, but the chief cook and bottle washer. I was grateful to have a great job, a supportive boss and amazing benefits. I would never say it was easy but I learned to do things I never thought possible. I repair things: the washing machine, the dryer, and the furnace. I recall a cold day in December when the furnace broke down the first time and we couldn't afford to get it fixed. Luckily, with help of online videos and supervision by Jason, I was able to pull out the motor and replace the pulley and belt by myself. I was the one who had to teach my kids to drive, pick them up from late night parties and discipline them. I am really lucky that I have such a great relationship with them. I am still learning something new every day.

Sometimes, I resent all the hard work I have to do. Honestly, what mom doesn't feel like this? Occasionally, I just want someone to take care of me, feed me supper and tell me everything is going to be OK. This is my disease as much as it is Jason's even though I am not sick. Nobody seems to get that. His bad days are my bad days. His sleepless nights are my sleepless nights. One of the stages of grieving is depression. I still get depressed now and again. I still get that feeling of not wanting to do or see anyone, or have mornings when it is hard to get out of bed. These feelings have improved since that first summer, but I have my moments. I really have to stop the spiral and take care of myself. It might be as simple as getting my haircut or as complicated as a weekend away. Like they say, "You can't pour from an empty cup". Airlines always tell you to put your face-mask on first for a reason. You are no good to anyone if you can't help yourself.

If I have any words of wisdom to share it is this; take time to grieve. The life you thought you had is over. I am not saying it won't get better, but all my priorities changed. We started a two-income family, to one income, barely making ends meet some months. We tried to keep the status-quo and not disrupt our kids' lives. I think I started the grieving process long before we got the diagnosis. I think I spent most of the summer of 2011 in shock. I remember seeing Jason so frail, the neurologist telling us that the good news was that it wasn't ALS, and this would be with us for the rest of our lives, "If you are going to have a neurological disorder, this is the best one to have." We spent a lot of time in the denial phase. When we were searching for answers, I kept hoping the illness was age related or from a medication imbalance, something that had an easy fix. I am glad it was not something worse. I still get angry. I kept wondering why this was happening to us. We are good people. What did we do to deserve this? I know I came to accept our new way of life a lot earlier than Jason did, but I wasn't using all of my energy healing, as Jason was. It was early in September, before he was diagnosed, that my dad and I built a ramp up to the front door. We don't often fight, but boy did we fight about that. I am not sure what we would have done when December hit and those few steps to the front door would have been impossible.

Grieving is different for everyone and those with this crazy disease have lost so much, especially mobility and freedom. This takes time. About a year before Jason became sick, he bought a little red sports car from a young guy who needed to pay his rent. His intention was to fix it up. When he got sick, we put it in the garage. I have mentioned many times that I would like my garage back and that we should get rid of the sports car but Jason's answer has always been NO! Fast forward 7 years and I think he is finally starting to think maybe the car should go before it is totally destroyed. I sometimes think the car is that little glimmer of hope in the back of Jason's mind and that someday he will be able to drive again.

Be flexible and patient. Yes, you had plans. Yes, he said he wanted to go. Yes, you were walking out the door when he decided that you should go without him. Sometimes I go, but usually I stay with him. Sometimes it is just 15 minutes that he needs to lie down and then he is ready to go, and sometimes he is out for the night. We all tease him about just resting his legs for a while.

Take time to laugh. When Jason first got sick, I used to joke that I always knew where he was, because he didn't move very fast anymore. He was usually right where I left him. We have always

been a family that enjoys the outdoors, whether it was camping, fishing or hiking. I remember the summer of 2012 when I worked so hard to keep things normal. I had never driven a vehicle pulling a trailer before, but we figured it out. It wasn't pretty but it worked. June 2012, we went to family camp with our scout troop at a wilderness camp in Northern Saskatchewan. Jason was in his scooter, sitting around the campfire cooking us beans with the biggest smile on his face because to the youth he was just Scouter Jason and they treated him as such. The youth were fascinated with his scooter and how he was going to manage in the bush. They were all stunned and laughed when I told them we didn't have to worry about bears because we could all run faster than Jason. For that first year, it was sometimes easier to joke about the situation because if you really thought about it, you would cry.

Do your research. Knowledge is power. When Jason was first diagnosed, he was just trying to hold on by a thread. He didn't care about the how and whys of the disease. He just needed to heal. I needed to know what to expect. I went to every appointment, asked questions and kept notes. Two sets of ears are better than one. From the beginning, I have known more about CIDP than our family doctor. There is lots of information out there to wade through and even the specialists can't tell you how it is going to affect your loved one since the disease is different for everyone. Finding the GBS/CIDP Foundation was a godsend. Without the Foundation, Jason may have never been taken off of treatment this year. Through the foundation we found out about Sub Cutaneous Gamma globulin (SCIg). By advocating for this different treatment, we were referred to a second neurologist who specializes in neuromuscular neurology. While doing tests for a new baseline they discovered that Jason might be in "Remission". A word we didn't think was possible. Will this be the new normal? At the time of this writing, he has not had IVIG in 7 months. I will be the first to admit, when he was taken off IVIG in January, I was frightened and very worried. While the intellectual part of my brain kept telling me that he was under medical care, and that they would never let him get to the point of being bed ridden and in a wheelchair again, the emotional part of my brain was a mess. I was a mess for the first few months. Last month we were apart for about 3 weeks and when I got home, I marvelled at how well he was walking and how good he looked. Like the story of the frog and the hot water, I had been immersed in the day to day, that I didn't see the progress. This leads me to probably the most important item, remember that behind the pain, the exhaustion and the medication, they are still the person you loved before they got sick. They are more than the disease.

