

## Andrew Edward Boyles

I have had Arachnoiditis since 1993, when I was 28 years of age. I am currently 57 and I have been suffering with the effects of this disease for almost 30 years.

Briefly, I would like you to know that I retired at age 50 in November 2014. I was at that time an executive with the largest telephone company in Canada, and my title was Senior Director Network Operations. I was educated at Dalhousie University, School of Engineering in Halifax NS Canada. I graduated with a bachelor's degree in Industrial Engineering (Distinction) in 1988 and I was a member of the Association of Professional Engineers and Geoscientists of New Brunswick, from March 1991 until May of 2015. I retired mainly due to having adhesive arachnoiditis and being in so much pain that I could not continue to travel, work long hours, and concentrate on the deep analytical and organizational tasks that had been my forte for many years.

My story begins in childhood. I was very close to my grandparents, and I spent many summers with them as a young child. My grandfather was a champion athlete in single sculls rowing, and his cousin was Charles Ingraham Gorman, the world champion speed skater from Saint John, New Brunswick Canada. He encouraged me from age 10 to start rowing in a rowboat. I spent countless hours practicing, and the hours eventually turned into years. My grandfather bought me an old racing shell when I was 13 and I practiced and practiced for the next couple of years. I would spend at least two hours a day rowing plus another hour doing running and light weights.

When I was 15 years old, I had my first competitive race which I won. I proceeded to enter various races locally in the eastern part of Canada and I won many of those as well. Things were going well. I was doing very well in school, graduating with highest honors from Junior High and on the right track to duplicating that in Senior high school.

I remember one day I was rowing against another boat when I was 16, and I was pulling on the oars with all my might, and I felt something "pop" in my back. From this point onward for the next 9 months, I could barely bend over or lift any sort of weights at all, and my training mostly stopped. This is the inflection point of all the future problems that I was to experience in my life. And I remember this so clearly in retrospect when it all went wrong.

By the age of 17 the injury appeared to have healed and I was back into competitive rowing again. I was weight training and running in the winter months and spending four hours a day on the water with only a half day off a week. By my last year in high school, I achieved my goal - I won the Canadian Junior Championship at the Canadian Championships Regatta in St. Catharines, Ontario. I was awarded an athletic scholarship from the Province of Nova Scotia, and an athletic scholarship from Cornell University in New York. I also won an academic scholarship from St. Mary's University in Halifax NS. I graduated with Math and Science Honors from my high school and won the Chemistry Prize in my senior year. Life was unfolding well for me.

When I went to Engineering school the demands of the program were very rigorous. I could not continue to row competitively and also graduate with the marks I felt were necessary to get attention in the job market. So, I stopped competitive rowing and focused on my studies. By 1988 I had graduated with Distinction from my program, got married and moved to a new province to start my career. I continued to go to the gym and participate in activities such as tennis and bowling

By 1991 I noticed that my back was getting very sore from playing tennis. The rapid movements were becoming difficult for me. I went bowling a few times until one time I went, and I ended up on the floor for almost two days with back spasms. I recall scraping the ice off the windshield of my car in the winter and collapsing in a sweat, in significant pain and not understanding why. Due to these events, I started my long (and regretful) association with chiropractors. I saw them regularly trying to get my back into normal condition, but nothing was working. During this time, because I did not have any x rays or radiology, I continued to lift weights and bike at the gym with the blessing of the chiropractor. In September 1992 I was lifting weights and at that time I felt my back "pop" and I was immediately in severe pain. I could barely make it back to my car and drive home. Later, after I was referred to a neurosurgeon, and subjected to a CAT scan and myelogram with the plaque-based contrast dye in my spine, it revealed that my L4-L5 disc was severely ruptured. I did not get my surgery until May 1993 - a wait of 8.5 months. During that time, I was off work, completely immobilized, and in the most severe pain you can imagine. I spent my days and nights on a hard floor, pillows under my knees, crying in pain, scared, with a brand-new daughter, not knowing what the future would hold for me. Would I ever get back to work? How can I survive financially? Many psychological stresses were layered on top of the physical pain.

My operation took place in May 1993 and after the surgery the neurosurgeon said, "I spent hours picking bits of your disc material off your spinal cord." Later (years later), I read a copy of his surgery notes and it said clearly that when he was operating on me his scalpel cut through the dura in my spinal canal. This is the defining moment of my life when unbeknownst to me, this event, this surgical mishap, set in motion the process of adhesive arachnoiditis in my spine.

It took me until April 1994 for me to get back into the office for work. My recovery was extremely difficult. I could not figure out why it took me so long to recover. Doctors had assured me that within six months of my surgery I would be "back to normal." This was not the case at all. I was off work from September 1992 until April 1994 - over 19 months in total. I was incredibly fortunate to have a boss who believed in me and went above and beyond the call of duty to make sure that I was looked after professionally and that my career would still be on track when I returned. Remember at this point I had been with the company for less than four years. To this day, this man, Mr. Robert Justason, is a close personal friend of mine, someone I look up to as a mentor, and a person that without his intervention to help me, I never would have achieved the success I did at work.

Years went by and all the athletic things I used to do were gone from my life. Rowing, tennis, running, bowling - anything that caused torsion to the spine or impact to the spine were "no nos." Depression set in. All I could do was walk, swim a bit, and ride a bike. By 1997 I was back to the gym doing light weights and cardio workouts on the bike and step machine. My back always needed babying = I could not sit for long durations as it was just too painful. I was back to work and, surprisingly, doing very well in my career. Unfortunately, my marriage ended that year. Part of it was due to all the stresses with my back, of this I have no doubt.

Gradually over time I was able to do some road biking and a lot of long walks. My back was never the same, especially with sitting. It was very painful to do for long periods. I had to stand up at work a lot during meetings and I got a lot of funny looks. I had to start explaining to people what had happened to me and why I had to stand. It was stressful and embarrassing. Today, I am so used to explaining it. I don't give it too much thought, but I still do feel somewhat ashamed that I have to do it, because everyone else in life can do it no problem at all. Having this condition makes it impossible to hide. Everyone knows there is something wrong with you, but they also are often embarrassed to ask.

When I met the woman who was to eventually become my wife in 2006, I was a physical specimen. I was 41 years old, I looked like a professional athlete with a washboard stomach, I was 6 ft 163 lbs. of lean muscle. I was going to the gym regularly. I had a constant aggravation of my back and my left foot, but it wasn't too bad in that I could walk 10 miles a day or more and still look normal to the untrained eye. In 2012 my wife and I bought a condominium in Las Vegas. I was doing very well at work - I had been promoted several times and was just below Vice President, a member of the executive team. I had up to 450 people reporting to me, I was at the top of my game mentally, I was in love, all my debts paid off - life was finally looking really good.

And then when I was doing some yoga stretching at home for my back in May 2012, I felt it "pop" again. I instantly broke out into a cold sweat. The next morning in bed I turned over and my wife and I heard a loud audible "snap." Unknown to me then, I had ruptured my L5-S1 disc.

I was in an indescribable amount of pain. I was off work immediately. I was in emotional and physical turmoil. At this time, wait times in Canada were getting unbelievably long for diagnosis and surgery. Luckily for me I was not alone, and my wife was working. We knew it was very bad. I begged my old neurosurgeon to operate on me because I was in so much pain, I literally felt they would just leave me like I was, forever. I was suicidal, for many months. I fantasized about hanging myself every day of my life because I could not bear to look at the future and believe the system would leave me untreated with no hope of getting better. Also, I was 48 years old and many years away from retirement. My house was paid, and we were debt free, but I was a long way from having enough money to walk away from the business and never have to work again - I needed to get back to work. Our future depended upon it. It was only through the support of my wife and my mother that I survived 2012, it was very close to the end for me.

So, I subjected myself to another disc surgery in January 2013. It did not go well. I never recovered properly from this surgery, and I had constant chronic pain in my left foot, leg, and back after the surgery. It took me almost six months from the time I had to stop work until I was able to start working again at home, and I started work only because I didn't want to get put on long-term disability, as my pension time would stop accumulating. I made my wife promise to quit smoking if I made it through the surgery and that's the best thing I can think of as a result of this surgery.

Gradually over the next two years I lost more ability to walk and sit. I was in constant pain, and nothing seemed to help. By October 2016, I was not able to walk more than 50-60 yards without having extreme pain in my feet and burning in my legs. I found out about a surgeon in Germany who helped a local friend in Halifax, and that is how I got in touch with Enande in Bremen Germany. I had MRIs done of my back and neck, because by this time I felt something was seriously wrong with my neck as well. And sure enough, L3-L4, L4-L5 and L5-S1 discs had disintegrated. I had no disc material left in the bottom three discs in my spine. Plus, discs C4-C5 and C5-C6 in my neck were also ruptured and almost no space was left in between the vertebrae. Dr. Ritter-Lang told me there were inflammatory cascades in my spine because there was no space left for the nerve roots.

In January 2017, my wife, my mother, and I travelled to Bremen Germany for me to undergo a five level Artificial Disc Replacement surgery. I had my surgery January 12, 2017, and at that time I was the first patient that had a five level ADR surgery at one time. The discs in my lumbar spine are made from titanium and a space age polymer while the discs in my neck are made of titanium, but thinner and using industrial made diamonds. The discs expected lifetime are between 65-75 years. Being 52 years old at the time I figured it was a safe bet that I would outlive their expected lifetime. We were in Germany for

a month recovering from the surgery. My neck recovered very quickly without more residual pain. But my left leg, foot and back still were not feeling normal. Why?

As time went on through 2017, it became apparent that something was wrong. I was still having severe pain in my legs, back and feet. I was on 60 mg of oxycodone a day and it didn't feel like it was helping at all. All of the MRI follow ups looked fine - the implants were exactly where they should be - the surgeon in Germany did not understand why I was still having pain. He suggested I come back for a series of tests and epidural blocks. I said no, that was not going to happen.

In desperation I began searching the Internet for the symptoms that I was experiencing. After many days of eliminating one thing after another I found a website in California that was <https://arachnoiditishope.com/>. It was created by Dr. Forest Tennant, a specialist in pain management. On the site there was a questionnaire which was designed to determine if you had a high probability of having arachnoiditis. I filled out the form and sent it via email to Dr. Tennant. I also sent Dr. Tennant a couple of CDs with MRIs and X-Rays. I remember when Dr. Tennant got back to me in early November and told me that I indeed did have adhesive arachnoiditis (AA). I can remember crying for hours, days even, trying to comprehend that I had an incurable pain condition. After all I had been through to find this out now was devastating. At that time, I was good friends with the Chief Medical Officer of my company, and he arranged to have me tested at Johns Hopkins International Hospital (JHIH) in Baltimore, MD. My wife and I travelled to JHIH and I had yet again another myelogram and CT scan. The diagnosis of Dr. Tennant was confirmed - I had adhesive arachnoiditis. And they wanted me to have a spinal cord stimulator implanted - I declined immediately as I knew the success of those devices was extremely low and the costs were astronomical.

My only hope was to ask Dr. Tennant what could be done to help me. Through a couple of very kind ladies on a Facebook site dedicated to helping Arachnoiditis patients, I was able to get an appointment booked with Dr. Tennant on January 15, 2018. Luckily my wife and I own a condo in Las Vegas and were able to drive to see Dr. Tennant. He examined me thoroughly and discussed my history and my radiology results. By this time, we both knew I had the disease, and the question was how was it best treated? Dr. Tennant created a custom protocol for me consisting of several anti-inflammatory supplements and injections, corticosteroids, and hormone treatments. I also was encouraged to use magnet therapy and infrared light therapy. I started this therapy immediately. Dr. Tennant told me that progress would be slow and that I was to keep taking these medications in addition to the oxycodone I was already on. He said that in perhaps 4-5 years I had a chance of being significantly better but there were no promises. I was fortunate enough to visit Dr. Tennant one more time in April 2018 before we went back to Canada.

I will be honest, there were no quick turnarounds. I was still having a lot of pain and while I increased my walking such that I was walking a km a day, in total, each day by mid-2018, I was still in a lot of pain and discomfort. However, I stuck to the protocol. By late 2019 I got into a very bad flare, and it lasted for months. In late February 2020 my wife and I travelled to West Covina, CA to explain it to Dr. Tennant, but we had very little time as we were called back to Canada because of the COVID-19 pandemic.

I was in awful pain and in desperation in early May my doctor in Canada allowed me to try Fentanyl patches instead of oxycodone. It was a "Hail Mary" request as I could not think of what else might work. And it was like my prayers were answered as within 10 days of using 37 mcg/hr. patches my pain level dropped by 80%. My life turned around almost immediately and while my total walking distance did not improve, my pain level had dropped so much that I felt I actually had a life again, after being in intense pain for so many years. And since May 2020, life has been significantly better. Removing the constant

level of pain I was experiencing was like lifting a huge weight from my shoulders. For the first time in 5 years, I was able to be happy again. I knew I would always have this condition but now my pain had dropped enough that I felt life was worth living again.

I still am on essentially the same protocol from Dr. Tennant as I was since January 2018. I have reduced my Ketorolac due to concern for my kidneys, but added other anti-inflammatory supplements based on Dr. Tennant's advice. Dr. Tennant has been my only hope for getting better or at least maintaining my condition. I am so thankful to him and all the help that he has given me. I believe I will be on this protocol for the rest of my life, and I hope that I continue to be able to feel as good as I have for the past two years. While I still have flare ups, they are shorter in duration and its longer in between large ones.

I hope my story will provide hope to those who are suffering with this terrible condition, and I hope the work the Tennant Foundation is doing will enable AA to be classified as a disease in all of the reference medical journals. Once this happens there will be even more hope for those afflicted as there will be more medical talent and money brought to bear to improve diagnosis and treatment.

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