

Long Journey Ends In Success

[Ed. Note: *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

I wrote an article for this site in January 2005 explaining how I came to find my syrxin & how it had effected my life. I now wanted to write an article to give you a good story update & some hope for others out there that you too can change your life with the right neurosurgeon.

I realised that a lot of people from this site didn't have good outcomes or were here trying to find out what else they could do to fix there condition but I'm here to say I kept getting opinions until I got the right Neurosurgeon that had the faith in what he could do.

I have had a terrible 6 years with my T4-T8 Syrxin & it effected my life to every aspect as I could only work 6 hours a week, rarely went out to meet people & having pain constantly everyday.

It was in November 2006 my Neurosurgeon thought my condition was worsening & began to talk about the option of operating on the Syrxin with putting a shunt into the Syrxin to drain it out. The procedure had huge risks with the chance that if they touched my nerve inside the spinal cord that I could be paralyzed & that just scared me so badly. The surgeon then said it was my decision to make.

Over the next few weeks I was a mess not knowing if I should go ahead with it or continue to live this life. I knew this life I was living from day to day on pain medication but at least I knew at the end of the day I could still walk & function so this decision became even harder.

I sought help at the chat forum in the hope I would hear some successful surgery outcomes but unfortunately I only heard from people that were getting worse or had bad outcomes.

This information made me a wreck & therefore made this decision so much harder that I decided to go back to my Neurosurgeon to ask him a lot more questions. He answered them all but the surgeon wasn't giving me any percentages of how I would come out of such a procedure & didn't really seem as keen to do the operation as he had last visit. He then said "If in doubt don't do it", but I thought who wouldn't be in doubt with a decision like this.

As the next few months ticked by I couldn't do anything but think of the decision I had to make but I was so lucky to have my parents support with my mum having gone to every appointment with me meant so much. As time continued to pass I was getting more anxious & it was now in my head 24 hours a day with me crying at night I would eventually cry myself to sleep. In March I decided a decision needed to be made otherwise I was going to be very sick as id lost 8 kilos..

The next week I had a physio appointment so I used this time to asked the physio for advice as to seeing another Neurosurgeon for another opinion & she suggested one. I made an appointment straight away but was very doubtful that even if I did like him how could I choose this doctor over one that's been treating me for 6 years.

I saw the new neurosurgeon on the 6th of March 2007 & immediately I liked the type of person he was. He was so relaxed & upbeat that he totally relaxed me & my mum as he introduced himself. We sat in his office while he studied my condition, questioned me about my pain & symptoms then proceeded to look at each mri with great detail. He explained it was a huge syrxin & went into what he thought about my condition & how it came about.

He explained that if I did have surgery on the syrxin he would also check to see if I had a Tethered Spinal Cord, though i'd never heard about this condition from my Neurosurgeon or the two other opinions i had years ago.

He then explained everything in so much detail & in our language so we could understand it. He said that it was likely I would deteriorate & that having children later on would be very difficult. His last words were "if you were my daughter I'd operate." He agreed I had no quality of life & he wanted to change that.

My mum & I both began asking numerous questions with him being very honest & patient. After being with him an hour we left his room both very quite but also full of a lot of information. We drove home talking about what he had said & I then said to my mum "if i have this surgery done he will be my doctor". I was just so comfortable with him & he just radiated so much confidence that he made me feel like he could change my life forever with fixing this condition.

I thought very hard over the course of the next two weeks with spending a lot of time crying with the worry. I was lucky to have my parents support right through this & I knew no matter what I choose to do that they would be behind me 100%.

In was two weeks later after a terrible day at work with my back & neck I went to my physio for some treatment. After talking with my physio she explained to me how excellent this doctor was & that she could only try to help ease with my pain but that this Neurosurgeon was offering to cure me. This really hit me as it was then & there that I knew I could no longer live like this with all my pain. I knew the risk was there for this operation going wrong but I had the utmost faith in my doctor & I knew that he would get me through this.

I rang on the Tuesday lunchtime to book in & he was so busy I was going to have to wait for 3 weeks which I didn't want to do as I was

terrified of coming out of it not walking. That was my biggest fear. Lucky for me he offered to operate on me on the Thursday which was his day off but of course I accepted as it wasn't going to be a long wait.

The day had finally arrived & I had my brave, caring but scared parents by my side. While I had numerous doctors come in & evaluate me about my condition, symptoms & medication I had so much fear of the unknown & hoped that I hadn't made this decision too fast.

It wasn't long & the staff had been called to get me ready for the operation to start, that's when I totally lost it crying & shaking while they wheeled me down to the theater with my parents walking behind. Just before wheeling me in I looked at my mum & said "I change my mind I don't want this done" but my mum held my hand & told me everything would be alright with tears flowing from both of us as my dad stood there he could only kiss me & say goodbye.

As I woke up I saw my anesthesiologist standing over my bed watching me along side some nurses. I immediately started to move my legs and arms to make sure I could do it all & luckily I was fine, it was such a relief. The anesthesiologist had a big smile on his face explaining the operation was a total success with them finding that I had such a badly Tethered Spinal Cord that when they cut the scar tissue it actually pinged back into place.

He said my Neurosurgeon then consulted with all the other neurosurgeons in the theater & decided not to touch the syrinx thinking that the syrinx was caused by the tethering & therefore it should shrink or disappear over the next few months. I was then wheeled back to my room to see my anxious parents waiting for my return to give me the good news.

After 24 hours I got out of bed to start walking & was home the next morning. I was told to just lay most of the time as I was in quite a bit of pain though it wasn't anymore intense to what I had before just harder for me to get up & down again. I did experience terrible headaches whenever I stood up for eight days after but that was quite normal for the procedure. When I started to try & move around more I felt like my back was breaking but that went quite fast as I followed the exercises that the hospital physio had given me.

It has now been 6 weeks since surgery & I'm just starting to feel difference in a way I find hard to explain. Before the operation I had a lot of tightness & stiffness that was so uncomfortable but now I'm feeling easier to move around without that intense pain all day long. I still experience pain but I'm not having to take my heavy pain medication as often as I was before & my aim is to get off all my medications completely. As part of my recovery I do my exercises daily, some walking & go to the local heated pool for some walking & swimming.

I am now so keen to get back to work, going out with my friends & in general just enjoying more life has to offer without that constant pain that had changed me as a person. I know its still early days & I'm still going to have a long recovery trying to strengthen all my muscles that are so weak but I know if I do this recovery right now it will be better for my future.

I have just been back for my check up after six weeks & my doctor was very happy with the outcome of the surgery & was very keen for me to get back to normal life as soon as possible. He said I'm right to go back to playing golf & getting back out on the water on a jet ski which I'm pretty excited to be able to have a go at again. He wants me to really test my back out to see how the pain level is when I'm doing normally daily duties as then we will be able to see how im feeling.

I will have another mri in three months time to see if the syrinx has shrunk or disappeared though I have the same confidence as my doctor that I'm sure it will be a thing of my past though its something I will never forget as it has changed things for me. I now look at life differently like I've been given a second chance to do all those things I want from my life.

I can only offer advice to people out there that this story might ring true for them if they haven't had surgery or have but it wasn't successful that you always have that option of getting a second. third or as many opinions as it takes to get the right doctor that clicks with you. I knew straight away that this doctor was in a different league to all the others & truly wanted to help me regain a quality of life. He was the only doctor that had ever mentioned a Tethered Spinal Cord & if it wasn't for his remarkable ability I would still be living with this today. Picking the right Neurosurgeon is what it all comes down to & lucky for me I picked the best one that I'm sure anyone would want to have operating on them. He said he wanted to change my life & I can feel its already starting to change & in a another six months I will be a new person.

I now have this Surgeon to thank for giving me a new start to my life & I will be forever thankful to him. I also have my two amazing parents to thank for standing by me over the last 6 years with so much love, patience & support they have definitely gone beyond the call of what parents do for their children. Without them I couldn't have made it through these last 6 years or had the courage to have this operation done but thanks to them I took the risk & did it. Finally I've had some good luck turn my way.

-- *Adriana*

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