

Travelling back and Update

We got the bullet train back home, so it took us just over two hours, I spent the journey in and out of consciousness with heat coming out of my head. It was better than I expected it to be, to be fair, but I was definitely glad that I had waited a while before making the trek. I think it was the happiness of finally being able to return home that got me through most of it.

I went straight from the train station to the nurse to have the clips removed. The hospital had sent me with the paperwork, clip removers, scissors and dressings, so I handed them over for her to familiarise herself with. She commented that prior to that week she had never heard of ACDF surgery and that I was the second person she had ever had in her care – I think I was too tired to be surprised at that point, but I remember my brain was trying to formulate some thought, it never quite reached one though.

Having the clips removed barely hurt at all, there was a slight tug on one that was in the middle, but the rest I didn't even feel come out of the skin. The nurse put them in a pot and I still have all 17 of them in my room. The incision looked really good, it was still healing nicely, and the 34 dots that now accompanied it were doing well too. I was relatively impressed with my consultant's handiwork and quite pleased that in time it would probably be unnoticeable. After securing a 2 week supply of morphine I finally headed home.

Most of my family came within hours, they just streamed in one after the other, I was happy to see most of them. None of them stayed long as it was clear I was exhausted, but it was sweet and short. I slept until late the next day then had the rest of my family round. Once they were all done, I was back to complete rest. The DVT stockings were still annoying as ever and my days were back to 3-5 hours long, I could finally stop forcing myself to try and stay conscious.

Above and beyond anything, I was missing one of my lecturers. I was supposed to see him before I left for surgery, but we never managed to meet. It was bugging me a lot, I really wanted to see him. I was determined to get out of the house and a few days later, I set out on a small journey. From the time I left my front door to the time I got back it had only been three and half hours but I had overdone it and was shattered beyond belief. I had walked to the dentist, (I knew half way there it was a bad idea, but I wasn't going back), then decided to go to campus to try my luck, it was a nice day and a lovely outing, but it floored me completely. I spent three days after that on more morphine than I was even on in hospital and totally out of it, I couldn't tell anything that happened in those days – I woke up to get ready and eat before fading out again.

My mum took the time to express the meaning of those DVT stockings then; wearing them for 6 weeks meant being laid up for 6 weeks, not strolling around – she had a point, I knew it then. That was the last of my bravery and after that I asked my friends to come to me instead, which worked out much better. I still wanted to get some fresh air every few days, but made sure I was out less than two hours. Most of trips were to collect books ready for when I am able to read properly again, and still plotting to see that one person.

Two weeks after my original floored adventure, I finally got to see my lecturer. I am not saying there is any direct correlation, but after 4 weeks of missing him, my pain levels finally had a vast improvement. I have always maintained missing people is bad for health. During those two weeks, I had begun sitting up more, my days were getting longer, chewing and swallowing were no longer an ordeal and slowly laughing was becoming less painful. Singing was still too much pressure and shouting was not a good idea but I could even gulp down

multiple tablets at once again now, which was a great contrast from having to have syrups and barely being able to open my mouth, as was the case directly after surgery for several days. Recovery was going very well.

The shoulder pain was practically none existent and only came after I had botched something up sleeping funny during the night. Pins and needles barely came and the tremors weren't lasting long if and when they did come, it was early days but it looked like surgery had made some difference. It was still too soon to comment on the pain front though, but it was clear even before I consented that there may never be any improvement, there was even a possibility of making it worse but only time will tell. I should add that it isn't representative of my life before surgery because, I am barely doing anything yet. As I return to more of my routine activities, that is where the bigger test will lie.

After a run of good days with no breakthrough morphine, I stupidly halved my dosage of continuous release morphine and paid the price, I had to reverse that back the next day. The good news is, I have my consciousness back, I am awake for most of the day now, and back to normal sleeping hours. There is the odd day when I have a nap in the middle, but on the whole I am very alert. The only down side to that is, is that I am now also prone to getting bored, however my vision has improved and I can read now. I am also able to concentrate better so watching programmes is possible, but sometimes I do still require my glasses. Practically forcing myself not to return to academics yet, though I have set everything in place for getting cracking as soon as these next two weeks are up.

I am four weeks post-op today. I don't iron or cook for myself, I still have to wear the DVT stockings in the heat but I am incredibly blessed to be doing so well. Mother, my family and our KFS family, alongside friends have been sending their prayers and well wishes, which mean the world and have protected this vulnerable time with great care. During this past week I have been able to completely update this diary, proving I can type with a good level of concentration and I have replied to a number of posts in our forum. I look back over my two year journey since being diagnosed and as our family here continues to grow, I remember how lost I was at the beginning, relate to the uncertainty and fear that initially plagues us all and now celebrate the difference in my psychology from then to now.

Last year was the greatest test, and the fear that consumed me then, was set free by changing my medical team. Having trust in their ability completely changed my feeling towards surgery, yes time helped me accept it, but ultimately there was serene peace in knowing they knew what they were doing. I would happily travel to the other side of the country any day to maintain that. I was adamant that something would go wrong, but maintained complete faith that even if it did, they would be able to deal with it sufficiently. I don't have the exact details of surgery yet, but I think it went to plan. The discharge forms read Anterior Cervical Decompression, uniplate and two 14mm screws. I am not allowed to take NSAIDs until December and will have imaging at 6 weeks, 3 months and 6 months respectively to check the fusion.

I am aware that the C3-4 disc is fragile and we don't know how it will react to this surgery, but I am no longer afraid. My pain levels may find no improvement but I am glad that I consented to this surgery. My third and final year of my undergraduate degree is around the corner and I cannot wait to start it. I am sat here smiling because it has been a well-documented journey getting here and I have come a long way since those initial terrifying days.