

Neurology and Medical Roulette

So, Neurology came around, I waited just over an hour to see the neurosurgeon but he was worth it. My uncle met me there to attend the appointment with me, the entire wait he complained. I was half happy he came, but every time I had to hear about what he would be doing if we had already been seen, I wanted to tell him to leave. He may have had better things to do, but unfortunately being there right then was my top priority.

The neurosurgeon was more with it than the spinal surgeon, he had bothered to read up on KFS and did not try wing his way through the appointment. He gave his opinion, explained very clearly what was wrong to both of us and answered every question my uncle threw at him (answers which I could have given him at a later time). I was very annoyed that he wasted half the appointment on elementary questions when I had waited ages to finally get answers from a qualified professional.

Regardless, the neurosurgeon detailed exactly where the disc had gone into the cord, the fusion etc. etc. I think it half scared the life out of my uncle as he grasped just quite how complex the problem was - but he was there by choice not force/request. We discussed the necessity of surgery and what it would entail, recovery etc. We were there for a long time. Eventually the neurosurgeon got round to testing reflexes and other neurological responses and was happy that I will still responding relatively well on the whole.

We covered lumbar very briefly, but I made it clear that it wasn't my pressing concern and manage that as of yet. We left with him needing to discuss my case at an MDT meeting and with the possibility of surgery looming quite near. What was stressed explicitly, was that surgery would not correct them problem, nor was it likely to help the pain - in fact he even told me it was highly likely to be a lot worse and that surgery was basically a preventative measure. For my own sake I decided not to dwell on it and just take it as it comes because I knew if I did I probably go rocketing towards a full blown breakdown.

The good side of having had my uncle there was that he then could answer the onslaught of questions from my family so I didn't have to, I just had to inform Uni. I told them as factually as possible and made it devoid of emotion. Once both my personal tutors knew, I released the general information to a whole lot of staff that had asked me to be in various projects or were expecting me to be around for one reason or another - I was committed to quite a few things at the time. In its basic form it said I had sustained damage to my spinal cord and was anticipating surgery. Some wished me well, others told me they didn't know what to say and of course the most common - most said nothing.

Awaiting the fate of surgery, I had to start wrapping things up and fast - my room needed adapting if I was going to be in it for several weeks, I wanted memories with my family and friends just in case something went wrong, I had a whole host of Uni stuff that needed handing over or finished, and that was all before I even got to concentrate on how I was going to complete my assignments. I was literally in a constant state of trying to buy myself time whilst my arms were both killing.

At one point, no idea what went wrong but it was as if they were burning from the inside, they felt like lead and moving them was somewhat like a weight-lifting session. In short it was painful. Fully aware that I was working on a potential time bomb at the time, my fear was that we were running out of time to have something to prevent. Luckily between being told I needed x-rays, the CT had been cancelled by the radiologist due to radiation exposure and the MDT still trying to make a decision, the symptoms began to ease. The decision was

however, I needed nerve conduction studies and an EMG to determine the extent of damage.

I had the x-rays, nerve studies and EMG (documented in a separate chronicle) then met with Neuro again - this time instead of finalising surgical details, he told me we were in heavy grey areas and Spinal had over-ruled him in taking my case. The nerve studies and EMG were inconclusive. We went over everything in quite fine detail and then I finally plucked up the courage to ask how likely it would be to lose mobility in my arms relatively soon - he repeated the whole load of neurological tests to reassure me he was confident it would not be soon. That was all I needed to hear and after that everything else was subject to opinion. Their concerns were not mine, I was beyond relief and joy that I didn't have surgery looming over me - I could decline consent if necessary without a worry.

After the whole build up to everyone thinking I was going to have surgery, family arranging to come down, a full-blown crying session in my god-father's arms (that was the last time I cried though over the possibility of surgery), and constantly changing what was happening in Uni - I was sure that this revelation was probably not going to go down well. But instead of being annoyed I think the relief was palpable from everybody. I no longer felt like I had a guillotine hanging over my head and I literally felt free. As great as the emotional relief was though, I didn't want to have to go through the entire explanation with anybody, but I did. I think half the world rang me directly that day - most were in disbelief that surgery wasn't going ahead. I lost the will to care what anybody else thought I was just glad I could say it was over.

Part of me was highly annoyed though, I was thoroughly exhausted from yo-yoing to the hospital and back for test after painful test. Some would say it was an anti-climax and all done for nothing, but if anything it is now a baseline for tracking how fast it's all degenerating when it all kicks off again. When I got home that day, I told them I wasn't having surgery or any more tests - in essence, I just wanted to be left alone. Nobody was having that though and they eventually convinced me to have the now re-ordered CT that spinal so desperately wanted and to see spinal's opinion through. I agreed just to keep the peace even though I really didn't care what spinal had to say now.

By the time I had the CT, the consultant that had vied for my case had left so I had been reassigned to a third consultant. I seriously did not have the energy left to care. I just wanted a nice long break from everybody and everything, so the month I had arranged to be in recovery from surgery I took to rest and recuperate from the pain in the hope I could finally come off of Cocodamol again.