

It started with a tremor (Part 1)

I had noticed a tremor in my left arm for a while, prior to that day though, sitting in my sociological theory seminar, it had always been controllable and never induced by holding up a sheet of paper. I was slightly concerned so I did register it with myself to mention it to my GP. Little did I know at the time it was going to open up a whole new chapter of events.

I went to see my GP several times in January due to my kidneys but it wasn't until a few weeks in that I finally mentioned it to her. I had been hoping the tremor would resolve itself like it had previously done, but it had been getting stronger instead. I told her about the tremor and she proceeded to test strength and grip etc. My grip had been weakened for some time on my right so that was no surprise. When I realised it had become bi-lateral my heart slightly dipped, the moment it became apparent I was also losing strength in both my arms, my heart plummeted to rock bottom. The shock hit me first, as it always does, the confusion, impact, and tears came later.

20th January, still half broken and having debated it for a few days, I realised I would have to tell Uni, I had seriously hoped that even though I always knew that this would be a possible eventuality, that it would not happen until after I had finished Uni. I had purposefully kept the more serious side of KFS off the table thus far and it hurt that they would now have to know.

I asked my personal tutor to meet with me and the following was a part of our correspondence:

'Am I right in thinking that medication isn't helping? [...] let's have a chat then and see what we can do to help'. It took me a while to form an appropriate reply to that, one that didn't reduce me to tears - all I could think was that I so wished medication could help. In the end I opted for *'its slightly more complicated than medication'*.

I was dreading talking about it, every time I thought about it I ended up in floods of tears, I certainly didn't want that to be the case in her office. It was all ifs and buts, heaps of uncertainty and what seemed like a time-bomb waiting to explode. The overwhelming fear was of losing mobility in both my arms, I could take a whole deal of things - but that; I wasn't prepared to see that through. Suddenly those nightmares that had bought me to the thoughts expressed in 'Realisations and Update' were now more imminent and an actual reality, not just a possible projection. The smallest things like brushing my teeth and doing my own hair became priceless abilities. My thoughts were full of despair and the over-riding thought was that I really didn't want surgery, that in itself made my heart stop cold.

I told my personal tutor as much as I knew at the time; I was losing strength in both my arms, my GP had requested an urgent MRI (just a short 6 months from the previous one) and I was being referred to orthopedics pending the MRI report. My head was in a complete mess - I didn't want surgery, but my bigger want, was to not end up with tetraplegia; both scared me senseless. The recommendations were to update the University's student disability service and to see a counsellor. After very little reluctance I did both the same week. The harder recommendation was to tell my other tutors; I told one - because he was the only other tutor who already knew the basic information (he originally shared an office with my personal tutor and had stayed in it for the initial meeting when I had to discuss KFS with her) and because I trusted him to keep it rationalised.