

Getting Promoted to Annual Review

I spent most of August and September 2016 preparing to move city. I was still having neck and shoulder pain but I was managing to have a lot of fun writing various academic pieces and preparing for conferences. I was relatively anxious about leaving all my support networks and everything I was familiar with, it was going to be strange having nobody to call if/when I got a pain flare up. I was doing fairly well though so returning to an exclusively independent lifestyle seemed possible. I was able to carry slightly more weight and was generally doing quite well.

I started my Masters degree in October barely on any medication at all, November through to December were relatively uneventful too. I was careful to keep doing plenty of stretches between the bountiful amounts of reading and writing. My sister helped me stock most heavy shopping when she helped me move so I never had to worry much about lugging shopping back. My senior tutor enlisted herself to deal with my book loads which was reassuring but I was admittedly reluctant to use the support. I did bring myself to on occasion, although that was only when I had great loads of books to return.

Whilst I was back up North in December I got discharged from my lumbar consultant, he was happy that my lumbar discs were stable. In any case, since my upper spinal problems had been improving symptomatically, they had stopped having a knock-on effect to my lower spine. I was quite pleased with my progress. By the end of December I was relatively sure my arms were doing much better too. In fact, I was very confident that the spinal fusion was complete because the tremors and tingling had greatly reduced too. Needless to say, I was fairly disappointed when January 2017 rolled around and my consultant at RNOH told me the fusion was still incomplete. Surprisingly, he was also concerned about the C3/4 disc which was bulging quite profusely. He warned that if any symptoms should return, I was to ring in and ensure a contrast CT was booked before I saw him in clinic. I did not share his concerns at the time so thought nothing more of his remarks.

Term two of uni started and the intense workload continued. Pain levels began to increase around February and by the end of March they had peaked to the point where I was between full doses of Cocodamol (60/1000mg) and Sevredol. I was back on painkillers and craving a massage to release the muscle tension but between having no time to go find a suitable professional, and not wanting anyone to touch me, I didn't see any type of professional, physio or otherwise. My energy levels kept dipping with the pain and probably from the exhaustion of keeping up with the pace at Cambridge, but somehow I managed to make it to the end of term once again.

I could not wait to get back 'home' at the end of term in the hope doing so would ease the muscular pains, but unfortunately nothing helped ease the pain. As the break from term progressed I resigned to the possibility my consultant was due a call and that I should probably book that CT he prophesised, but I didn't. Upon returning to Cambridge I went to see my GP and told her that I could not stay on Morphine during term because I needed to be able to write up my dissertation.

Conducting research whilst running on a fairly low battery had not been a problem because in most cases I could do it from the comfort of my own house, at my own convenience. Thankfully, I was not required to travel and expend energy I did not have at the time. Even transcribing interviews and analysing data was doable at my own leisure so it did not really matter how much pain I was in for either of those. To write however, I needed to be able to think clearly and concentrate, neither of which were possible if I was taking high doses of

painkillers, which for the first time ever were having the unusual side effect of knocking me out.

My GP understood that Sevredol was probably not best, nor was starting Gabapentin because that also came with caution of drowsiness. We eventually came to an agreement of trailing Meptid which is basically synthetic Morphine. I am not entirely sure if I was taking the correct dose but initially that too wiped me out, ironically though, unlike Morphine, it wasn't even taking the pain away. Eventually I began to tolerate the Meptid and as pain levels decreased I was able to start drafting my dissertation. After much internal debate I also contacted my medical team in April and arranged the CT scan. Due to the flash return of symptoms, a MRI was also requested.

In line with delivering top notch, convenient care, I had to wait a short while so both scans could be done on the same day to save me travelling back and forth to London. I was back in the scanners in May but by that time pain levels had begun to decrease, and as they dropped so did many of the symptoms. My theory remains that it is swelling which presses on my nerves during flare ups to cause symptoms as opposed to bulging discs or herniation. Both scans were done in record timings it seemed, I was practically in and out of the hospital within an hour.

Due to the fact my dissertation deadline was speeding towards me and I was still editing 18k something words, my medical issues had to be side-lined. For my own sanity at that point, I needed to finish and submit my dissertation without taking an extension so I could get out of Cambridge. Once it was done and gone, it would be over, and I would be free. I did not want or need to prolong that eventuality. I did however, for the first time ever in my academic history, seriously contemplate the possibility of utilising an extension, but in the end sheer determination over anything else had me plough through.

My dissertation wasn't ready to print until the evening before submission, and I casually walked down to the printers at 9am on the day of submission despite the midday deadline. I was passed stressing at that point. Both of my hardcopies were submitted shortly after 10am and I took great pleasure in instantly announcing the achievement to the world. It is the latest I have ever submitted anything, but I still did it before the deadline so that is all that matters. I was very proud of myself, more so because it meant my Masters degree was finally over. I was ready for a very long break, and to tackle getting my muscles sorted as a matter of priority.

I arrived back to Manchester early June and realised I was yet to follow up my scan reports. In my own defence, I was hit with one joyous family event after the other and my attention was continuously required elsewhere. Nonetheless, my consultant's secretary promptly replied once I emailed her and was extremely happy to relay that the surgical fusion now appeared complete. There was no concrete explanation for the flare up or pain but I was reassured that everything would be discussed at my next appointment.

Whilst I spent a considerable time resting and managed to come off my painkillers, the shoulder pain continued to refuse to let up. I started doing excessive stretches in the hope they would help, which they have to an extent but the muscular pain is still present even if I do have a greater range of movement back. By July I was completely drug free once again and only in mild pain. At some point I was pleased to note that I am now able to travel without ending up in residual pain, a luxury which has taken a long time to return. I was relatively pleased that my neck wasn't being a pain but I had no clue how to alleviate the fluctuating pain in my trapezius muscles.

On the 31st July 2017 at 17:30 I passed all neurological tests, and my medical team affirmed that both the CT and MRI scan indicated the fusion is finally complete. To add to the delight, I was also told that the C3/4 disc which was previously causing concern, is now relatively fine and that there are no concerns at all. The report from that review read '*Today she has no radicular symptoms. Clinically she was showing normal tone, power, sensation and reflexes in the upper limbs bilaterally.*' The letter ended with '*We will review her again in 12 months with cervical x-ray on arrival.*' After 3.5 years, many ups and downs, I finally got my wish of being promoted to annual review, thus my choice to bring these chronicles to an end on this monumental highlight.

I am being referred to physiotherapy for my shoulders and hope that the muscular cramps and pain will ease in time. I will be starting my PhD in October in the fascinating area of genetic editing on human embryos. My research will explore the possibility of a future in which genetic diseases and disabilities can be edited out of the human race and what such a possibility could mean for individuals who have a genetic disease and want to reproduce. My interest in genetics and embryology emerged long before I was diagnosed with KFS, however I am now in a very privileged position where my research interests can potentially be enhanced by my personal experiences. I am aware 'Chronic Academics' is an emerging area so it is possible I may write again one day...