

Having suffered with migraines for years and trying a number of different medications my GP referred me to the neurology dept at the hospital, after waiting 6 months I finally had an appointment on 8th February this year where I discussed my symptoms and requested an MRI scan. I had the MRI scan 4 weeks later on 11th March. I was driving home from work on 14th March and I had a call from the hospital asking me to go in the following day to discuss the results and that I should probably bring someone with me. I knew instantly that it didn't sound good but tried to stay positive. The next day the neurologist told me that the scan showed that I had a large Meningioma in my occipital lobe, these tumours are usually benign and slow growing but as mine was already quite big I would need surgery to remove it as there really was no other option. What a shock! I don't know what I expected to hear but it wasn't that. I was told the surgery would probably be within weeks, it was a lot to take in. I had bloods done there and then in preparation and cried all the way home.

I had an appointment with the neurosurgeon at UHCW on 14th April, he showed me the MRI scan and I was shocked at how big the tumour was (5.9cm), we discussed the surgery and the risks and he basically told me it had to come out and he would prefer it to be sooner rather than later so he added me to the list and I just had to wait for a date.

The not knowing drove me mad, when would the surgery be? Would I be ok? What if I wasn't? Should I have it? During this time I continued to work and I hadn't told many people my situation, partly because I just wanted things to be as normal as possible and partly because I'm not good with sympathy and didn't want people treating me differently, I think there was also a part of me that thought if I didn't talk about it then it wasn't happening, although it was constantly on my mind and I thought about it from the second I woke up until the second I went to sleep and every second in between!

Finally I got a date for surgery, 4th May, at least now I knew. I planned to finish work on 29th April which meant I could isolate prior to the surgery however this didn't work out. I went home early from work on 28th April as I felt unwell with a migraine, that evening I was very sick and collapsed on the bathroom floor, my husband and kids were in Leicester watching the football so I had to call them to come home before half time. My mum and dad were away and my sister couldn't get in so I was home alone with my sister parked on my drive talking to me on the phone until they arrived home from football, when they got home it was decided to call an ambulance for me, after 2 hours on the bathroom floor I was cold and shaking and just wanted to get in bed, they managed to get me in bed and settled and with still no sign of the ambulance they cancelled it. I still felt the same in the morning so another ambulance was called, after a few hours it arrived and it was decided to take me to UHCW to be assessed, on the same day whilst waiting for the ambulance my surgery scheduled for 4th May was postponed due to an emergency as they were, up until then, unaware of what had happened with me, if they were it may not have been.

After spending almost 10 hours in A&E and having various tests, scans and bloods taken I was moved to a ward where I was put on IV fluids and a number of medications. My electrolytes and blood sugars were low, I hadn't taken in any food or fluids for over 24 hours and my weight was too low. They needed to build my strength back up ready for my op. The surgery was rescheduled for 11th May and it was decided they would keep me in until then. I got stronger and had a lot of time to think, trying to stay as positive as I could but there were times when I broke down and thought I couldn't do it.

10th May, the day before my op was one of the worst days in my life so far, thinking that I might not ever see anyone again, or things might not be the same after surgery, just trying to get through the day the best I could but I don't think I have ever been so terrified in my life. Visiting time came and saying bye was so hard, I cried a lot and for a long while afterwards. Surprisingly I slept quite well, woke up had a shower, put on my gown and I FaceTimed Lee and the kids before they went to school and then boom I was ready, let's do it! I was taken down at 8.52am, I remember the time as I sent my last text to Lee. I woke up in Critical Care at 7.15pm, although I was a bit out of it I actually felt ok, the op was a success and they believe they had removed all of the tumour, my blood pressure was a little high and fluid was being drained from my brain but they were hoping to move me to a ward the next day. I had an ok night, not much sleep, a little uncomfortable, very thirsty, wires and cannulas sticking out of me everywhere but all was good...I was alive!

I spoke to Lee on the phone the next morning and he and my mum were coming to visit at 11am, I was counting down the hours, couldn't wait to see them. I was sitting up, I'd even had breakfast and a cup of tea by the time they got there and they couldn't believe how well I looked. I did it, I actually did it! I was moved to the ward later that day. The drain was removed and I felt quite well although very tired and I kept hallucinating when I closed my eyes which worried me slightly, although when I mentioned this to the doctor he said it was quite common after surgery of this kind and it could also be a side effect of the medication! Phew! (This lasted a few days) I was assessed on my walking ability, vision and movement on 15th May and spoke to the consultant who said I should be able to go home the following day!

16th May, 5 days after a 7 hour craniotomy and 18 days in hospital I was discharged, never felt so happy to be going home where I belong and to see my family and friends! What a journey!

When I first arrived home I spent almost every day in bed and slept so much but woke up at silly times during the night for hours on end but it did get easier and after a couple of weeks I was making it downstairs for a few hours at a time, I had my staples removed 11 days after surgery and the wound looked to be healing well. I had a follow up appointment on 26th June with one of the surgeons who were in my op who was happy with how I was progressing although when I asked if I could go on my holiday in July he said I couldn't fly as they prefer to see the results of the follow up MRI first but would check with the lead surgeon (my MRI not until August) What a blow, this really upset me because as a family we really needed that holiday but there would be other holidays so although really gutted we knew we had to cancel. We requested a letter from the consultant stating that I couldn't fly and the reason so that we could get a refund on our holiday and to our surprise the decision to let me go was overturned and the lead surgeon said I could fly after all. This still worried me and after days of should we or shouldn't we go we bit the bullet and decided that if anyone deserved this it was us.

On 18th July, 9 and a half weeks after my surgery I returned to work, this was only on a part time basis for 4 days but was a step in the right direction and something I wanted to do (I work in a school so it was coming up to Summer holidays)

A week after we jetted off on our hols, although very hot and very tiring the holiday was just what we needed and even though I have non stop slept since we got back we had the best time with some of our best friends and the flight was fine.

I'm still suffering with tiredness and fatigue and other people who have been through the same have said this can last months and maybe even years so I guess this could just be a new way of life that I have to get used to. I'm taking anti convulsant medication which I will continue with for at least a year to prevent seizures which up to now I have not suffered with pre or post op and I'm still waiting to hear back from DVLA regarding my driving license but my consultant did say I couldn't drive for 12 months so I'm following that advice until I hear differently which you don't realise how much this impacts you until it happens, luckily I have a very good friend who has offered to take me to work and takes me out when the 4 walls get too much! Thankfully there have been no migraines since April and I hope it stays that way.

One thing I will say is just because I'm smiling doesn't always mean I'm ok, some days are harder than others but I'm still here to tell my story and I couldn't have done it without my amazing family and friends.

Life goes on....

Don't sweat the small stuff!







