



Amy's Story

My story began in September 2017. I was on holidays in Wexford with my family and developed a bacterial infection in the right side of my face and neck. I had this lump sitting on my jaw line, but thought nothing of it after being diagnosed with the bacterial infection. 3 months passed and this lump was still there, and slowly growing in size. After 3 visits to my doctor and being told those 3 times it was an infection in my salivary gland, I begged her to listen to me. The lump wasn't sore, it was just getting bigger and I was worried. She called in another doctor for his opinion who said I needed an urgent ultra sound on this. I had this done a month later on the 22nd of February, with no new information. He had never seen it before, so referred me for a CT scan on my neck and face. I had this done on the 22nd of June and was rang by my GP receptionist who told me over the phone that this was a 'lipoma' which was a benign tumour of fatty tissue. The next week on the 28th of June, I had the ear nose and throat specialist who I had been waiting to see. He told me he wasn't convinced that's what it was, and wanted to do a biopsy and an MRI for more information. He was quick with this and I had my MRI on the 18th of July. That's the day things started to go downhill for me. I had a weird on/off headache, which I researched online and found that an MRI can leave you like this. I had this for a few days, and actually took my fiance aside one day to tell him I thought I was going crazy. I was seeing shadows and I felt like someone was just behind me all the time. I kept seeing things float past in my peripheral view, and I was concerned I may need help.

On the 28th of July, I was at my uncles 50th birthday. I felt a heavy cloud of pain hit my head so hard I needed to go and lye down there and then. The pain eased a little, but over the next 3 days progressed quite a bit. I started to vomit up my food, then my water, then my medication, until I wasn't even able to stand up. I rang my doctor on the morning of the 31st of July and told the receptionist I thought I was suffering a migraine, but I've never had one. She asked me was it the worst headache I've ever had, to which I replied "yes!!". The doctor rang me back within minutes and told me to go straight to A&E as it could be a clot or a haemorrhage. My only thoughts were "that could hardly be happening to me!". After thinking about it a little more and speaking to my fiance about it, he convinced me to go to the hospital to get checked out. Better safe than sorry!

When I got there, I was taken straight into a cubicle and put on a drip as I had light sensitivity and was severely dehydrated. I told the doctor it may just be a headache from the MRI I had just over a week before. He went and found the results of my MRI and came back to tell me that I had no lipoma, which I was quite pleased about. Instead, the muscle in the left side of my face had worn away, and he couldn't give me any reason why. I didn't think much of it to be honest, just thought it was a bit strange. Because of those results, he decided to do a CT scan to see a full image of my head and brain. He came back 20 minutes after this scan and took me and my mam into a small room for privacy. He told me it looked like there was a clot in my brain, but they needed to do another CT scan with

contrast to confirm this. He took more bloods and added cannulas to both of my arms. I was brought in urgently for another CT scan and 20 more minutes later, he came back to tell me that I had a left transverse venous sinus thrombosis, which meant I had a clot in one of the major veins draining blood from my brain. He said the reason I may have lost facial muscle would have been due to lack of blood flow to the region for months. I didn't realise how serious it was. Everyone around me looked so worried, and I heard nurses and doctors walking by my cubicle talking about "the girl with the clot in her brain". Everyone was peaking in and I was getting constant medical attention. A doctor came in to take a history and what I told her was not true at all. My fiancée was there correcting me, but I was so confused about everything I had no idea. I began clexane injections that night.

I was kept in hospital for 3 days and sent home as there was nothing else they could do. I was kept on clexane and started on warfarin a few days later. Any issues or concerns I've had have been dealt with and talked about with great patience and understanding. My neurologist is only a phone call away and my hematologist is doing a case study on me, as this is quite a rare condition. The chances of me developing this were 5 in a million.

At first, I was told it was all from my birth control pill, but I've had an abundance of blood tests done to find out if I have a clotting disorder, which is still inconclusive. The parameters for lupus anticoagulant are 0.7 - 1.2. Mine is currently sitting at 1.3, which means I have to stay on warfarin for the time being. Usually, a positive result for this would be up at 2.2 or higher, which is why testing is still inconclusive for me.

I've developed what's called Idiopathic Intracranial Hypertension from this, which can be excruciating at times. I get pressure headaches when I laugh, cough, sneeze or bend. I recently had a lumbar puncture and CT scan to diagnose this. The clot was so big, that some of the residue has solidified to the lining of my vein, which means it's now unable to absorb the spinal fluid like it should.

I'm currently taking 2 stomach tablets, warfarin, and cerelle to keep on top of everything. I'm lucky to be here and I know that. Had I left it any longer, I may have had a stroke and more than likely died from this. It's unnerving to think about, but I count my blessings everyday. It's been a long 2 years and I'm now 13 months post diagnosis. I never thought this time last year that I would be living the life I am now. There's a lot I can't do due to medication, but you have to try not to let those thoughts take over, and keep going for the people you love. They're the ones who give me strength to not let the illness take over my life. I now see the world differently, and I know the people who have been there for me have been amazing, and they're the ones who count and make life what it is. My anxiety I am dealing with, along with my stress levels as they have a bad effect on the chronic headaches I suffer.