

My Experience in a Myasthenic Crisis

Sunday

I was watching Breaking Dawn and didn't go to bed until nearly 1.00am. It was a normal morning, I woke up before 9.00am, I went and got breakfast, got dressed, went on my laptop then after a while I got tired so I closed my eyes and fell asleep. It was the afternoon when I woke up and I was in pain with my neck and when I moved I went dizzy, it was horrible then in the evening I kept getting sharp pains in my ears. I had my tablets and went to bed.

Monday

I woke up normally, went and got breakfast, I struggled to eat all of it. I went and got dressed. My dad phoned up the Drs and got an appointment. I went down the Drs, he listened to my chest and said it was clear, he looked in my throat and he didn't like the look of it, so he took a swab and gave me antibiotics just incase there was an infection. I didn't go to college, I stayed at home and I just kept sleeping.

Tuesday

I woke up about 7.50am came through to the sitting room and laid down and went back to sleep, I was sleeping on and off until the afternoon. I brought up some phlegm so I got up and went to the bathroom. Then I realised that I needed the toilet so I started to walk towards the toilet door, I could feel my legs starting to go. I opened the door, went in and went to shut it

but my legs went and I fell backwards. It was a good thing the door opened outwards otherwise I would of banged my head. I tried to call for help but because off my throat I couldn't shout and my phone was on the sofa. Dad did come through after a while but it felt like ages, my mum helped me to get up and she helped me to get to my bedroom, I sat on my bed. It was time for bed so I had my tablets. I got up to go to the toilet, I got to the bathroom door and I had to get mum to grab a stool so I could sit down then. I had to move from the stool to the chair then to the toilet then use the chair again. Then I got from my bathroom to my bed. My mum had to get my dad to help, he was in bed as he was at work early next morning, he phoned work to say wouldn't be able to go in as I wasn't feeling well. Dad helped me as well too sit down, and then I shuffled up to the top off my bed, laid down and went to sleep.

Wednesday

Dad came down to give me my 6.00am tablets he managed to get one in to me. I was trying to move myself up the pillows but couldn't, everything felt like it was heavy, I couldn't move my left leg without help from my right leg, it felt like I was paralyzed I even thought that I might of been. My mum phoned for a ambulance, I was trying to sit up so I could breathe properly. A couple of times my head slid off the pillows and I panicked because I couldn't breathe. After a while I could start to move a bit but I was weak, when the ambulance drivers went to get me on the stretcher I couldn't hold my head up. I wanted the toilet before I went but I couldn't get there, when I got on the stretcher It become a little easier to breath because I was sitting up. I was took to A&E, the drivers had the blue light on all the way, when we came to traffic lights and round abouts e.g. they put the siren on because the drivers were concerned that

I needed my neostigmine sub cut. When I got to A&E I was assessed but still didn't get my neostigmine until 8.00am I still needed the toilet, they got me a commode, when I went to get up off the commode my knees went and I fell on the floor. mum and the nurse helped me up back on the bed. When I was stable I was moved to ICU. I had a arterial line and a canula in. I was wired up to a stats machine. I needed the toilet but my nurse wasn't happy with me standing because of what happened in A&E. I used the hoist I didn't like it one bit!. I had fallen asleep in the afternoon/evening, I had woken up and my throat felt big like and I only had a tiny gap left, it was really hard to breath and I felt weak, my legs hurt when I moved them my and my arms hurt when I lifted them. I had asked for the neostigmine sub cut. it took a while for them to get it, I couldn't sit up, I had to stay laying down. I couldn't even sit up on the pillows. as soon as I sat up a little it felt like my airway was blocked completely. when I was laying there I thought they were going to come through and say they are going to put me on a ventilator. It felt like hours and I was really scared I just kept thinking "I don't want to die" , "dad will be the last person I see" and "I won't get to see mum again or my sisters" I finally had the neostigmine sub cut and I started to feel better.

Thursday

I Woke up at 5.00am and texted dad for a drink and I needed the toilet. when dad took my mask off my throat felt big and it was hard to breath, my legs hurt when I moved them and my arms hurt to lift. I couldn't lay down completely like before I had to sit up a bit, it didn't take as long for them to get the neostigmine sub cut, I had it and after a couple a minutes I started to feel better. I stayed awake after that. I was scared that if I went back to sleep it would happen again or I

wouldn't wake up again. all I could manage for lunch was a table spoon of macaroni cheese. I had the adult neurology/respiratory Dr come round, I was to stay on ICU because I wasn't stable enough to be moved to a ward. she asked me if I could lift my legs but I could only lift them a 1cm if that. Once she left I had to have my neostigmine sub cut again. I had to have stockings on and a injection for thrombosis. all I did after was just laid there it was hard to move and it hurt with the canula and arterial line in. late evening I wasn't very good because of this mum was late home, I was struggling to breath, it felt like I had a tiny gap left but not as bad as Wednesday night. I had another injection. Mum and dad were getting worried like Wednesday they thought I was going end up on a ventilator. I was still using my phone/iPod/ to talk because my throat was still painful. Today was my 17th birthday but I was ill to celebrate it. I had the canula out and when they took it out it was bent and the nurse said it was too small. It was the size you would use on a small child that's why it hurt so much when I moved and when they put the antibiotics in.

Friday

I woke up the nurses sat me up and I had a wash than I sat in a special chair, I had some breakfast, I had my arterial line out, I could then move properly but still had the stats machine on, I ate most of the macaroni cheese. Mum came up early, in the afternoon my friend Chloe came up to see me, it was nice having her there, she made me laugh a bit. mum and Chloe went to get a drink, I had fallen asleep, I woke up and they weren't back so I pressed the button to a nurse because I was desperate for the toilet and wasn't sure when mum and Chloe would be back, The nurse come through and I just managed to say toilet she went to get a commode. mum and Chloe came back than the nurse came back they sat me up I sat on the edge of the bed but couldn't get

up, if I got up I didn't know if I could get back to the bed, I asked for the neostigmine sub cut. I was helped to lay back down then the nurse went to get it. I had the neostigmine sub cut then went to the toilet. I laid back down, I starting coughing and I starting bring up phlegm. the nurse went to get the physio and she helped me bring it all up and relaxed. my friend got scared/worried because I was struggling. My sister and brother-in-law came up to see me in the evening my sister was scared to come near me, my brother-in-law wasn't scared to come near me. They went home. a little while after then mum went home early to take Chloe home, I got ready for bed put my mask on, got my phone and cuddled the toy dog my sister and brother-in-law got me.

Saturday

Dad said I refused to take my 2.00am tablets so I had to have my neostigmine sub cut at 5.30am and had my tablets at 6.00am but I can't remember refusing it. I didn't wake up until 9.30am and took my tablets at 10.00am the Drs came round on their ward round and Dr Garfield said to my dad how did he feel about taking me home?, but he had to talk to Dr James first to agree with this. My mum arrived with my friend Chloe. Dad told my mum I could go home but she didn't believe him, she thought he was joking, but she found out it was true. My dad had to go home and get some clothes/shoes etc. We had to wait for my medication/antibiotics from the pharmacy. In the meantime i was hungry so I made my mum go to Costa & get me a tuna & cheese Panini. It wasn't long after that, that my medication came up & my dad got here. Dad had to bring my wheelchair as I still couldn't walk, My friend Chloe came home with us & we watched a DVD together. It was really nice to get home, I missed my dog Holly, and she was really pleased to see me. And

it was really nice that I could go to the toilet rather than sitting on the commode.

Injections

I don't know how many injections of neostigmine sub cut I had all together, I can't remember but I do know that I had quite a few.

Medication

I came home on the understanding that I had to carry on having my Mestinon tablets every 4 hours round the clock, The extra dose at 2.00am is helping me. I am still waiting for a follow up from my Consultant.

Wrote by myself

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