

# MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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## BRIEF OUTLINE OF ANTI-NMDA RECEPTOR ENCEPHALITIS

Anti-NMDA Receptor Encephalitis is a recently discovered (2009) life-threatening autoimmune disorder associated with multi-stage neuro-psychiatric symptoms, with a varied prognosis that is difficult to predict, even with treatment.

The term "Encephalitis" means inflammation of the brain.

Anti-NMDA receptor encephalitis is a disease occurring when antibodies produced by the body's own immune system attack NMDA receptors in the brain causing neurological, physical and psychiatric symptoms.

NMDA Receptors are responsible for: learning, memory, judgement, perception of reality, human interaction, the formation and retrieval of memory, control of unconscious activities (such as breathing, swallowing etc.).

This disease is still considered rare, and very new in medical terms, which means medical research is still very new and un-tested.

Treatment options is still widely debated around the globe, with a high degree of variation from one Doctor to the next.

Recovery is generally slow and may occur over months or even years. The recovery process is often complicated by many ups and downs, and by fears of relapse or re-emergence of symptoms.

It is known that the majority of patients continue to experience symptoms after they have had treatment - anywhere from months to years after treatment. This does not mean that the treatment hasn't worked, it is simply an unfortunate characteristic of this disease.

Full Recovery can take many years after the last episode, however some patients may not ever recover completely, having permanent physical disabilities or permanent brain damage.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

I am a 32-year-old female, living in Brisbane Australia with my husband of 3 years and my Great Dane (who is my baby!)

I have been taking anti-depressants for a number of years for Borderline Personality Disorder. In November 2015 I didn't have a regular GP after recently moving. I felt like my medication needed reviewing so went to a GP at the local medical centre. He completed a standard Mental Health Assessment Questionnaire and decided to increase the dose of my medication.

A month later I felt like something wasn't quite right, but couldn't put my finger on it, so I went back to the same Doctor who told me that I should give it some more time, as it may still be in the adjustment period.

I had a couple of episodes at work where I felt like I couldn't keep my eyes open and was getting a migraine (which I don't get), but the headache part never actually eventuated. Each time I had to go home and when I got home I slept for the whole rest of the day and night.

I normally love Christmas, and prepare ages in advance, but this year (2015) I somehow forgot to do anything, so we didn't really celebrate Christmas at all. And I spent the next few weeks feeling angry for no reason. I couldn't shake the anger, and I was taking it out on everyone around me.

By January 2016 I had dropped from my normal 50ish kg to 38kg, because I was forgetting to eat for days at a time, which is out of character for me. I have always been petite, but always had a healthy appetite and love my carbs and snacks.

In January 2016 I passed out a couple of times at home, waking on the floor covered in sweat. I also picked up a couple of staphylococcus infections and gastro-flu (which lasted 4 days) and knocked me around a fair bit. I couldn't put my finger on it, but I just generally felt really unwell.

In February 2016 I passed out again after getting out of the shower, and woke on the floor of my bedroom covered in sweat.

I had a few more episodes at work where I felt like I couldn't keep my eyes open. I had to go and nap in my car a few times because I was worried about driving home. My head felt really heavy, but again no headache came on.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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Sometime around February or March 2016 I started hallucinating. At first it was small black shapes running across the room. Then it progressed to hearing gecko's catching insects. Then one day, every time I closed my eyes all I could see was a steak knife floating around. I put it down to stress from work, or maybe a side-effect of the increased dose of my medication. I wasn't too worried, and I thought they would just go away. I am not exactly sure when they started, or how long they had been happening but I think it was around 6 weeks. I am also not sure when or how I realised that these things I was seeing and hearing weren't real.

After a few weeks of these hallucinations, they got worse. I started feeling like the steak knife was dragging across my skin, cutting me. I could feel the pain of the knife cutting into me, but when I looked at the spot there was nothing there. And I started feeling like things were crawling on my skin all the time, which made me want to scratch my skin all the time. On one occasion at work, my colleague grabbed my hand because I had been scratching at my wrist for so long it had started to bleed.

It was also around this time (March 2016) that people at work started to comment that my normally phenomenal memory was lapsing, I was missing things, making mistakes and generally lacking in my ability. I was also losing my temper to out of proportionate levels at colleagues and contractors. On one occasion I lost my temper so bad that I paced around the carpark at work and chain smoked 40 cigarettes in under 2 hours (at that time I was smoking 20 per day), and refused to return to my desk. I even had a colleague ask me if I had recently developed a drug habit!

I was forgetting to drink any water all day and getting so dehydrated, and forgetting to eat all day, but never felt hungry.

At home, my husband noticed that I was losing my temper and picking fights with him over nothing, both which are totally out of character for me, and I was pushing my family away, refusing to speak to them for long periods of time for no real reason.

I had also started sleeping a lot. I mean stupid amounts. More than 15 hours in one go without waking. I slept through alarms, had conversations with people in the morning and would go back to sleep and not remember any of it, and not re-wake for another 4 or 5 hours.

The hallucinations were getting worse and worse, and during one of the particularly bad ones I got the steak knife and sliced my toe nail in half, and dug into the flesh around my toenail with the knife to see if it felt the same as the hallucination feeling, but despite how badly I attacked my toe with the knife, I couldn't feel it at all. My toe ended up getting infected.

After this incident I realised something wasn't right. At this time, I wasn't calling them hallucinations, I didn't exactly know what to call them as I had never experienced anything like this before. I knew in the back of my mind that it wasn't real, but I could still see, hear and feel these things.

I didn't want to tell my family or husband or any of my friends what was going on because I was scared I was losing my mind, plus I didn't exactly know how to explain what was going on without freaking them out. I mean, how do you tell someone that you have been seeing things, and then you attacked your own toe with a steak knife to see if it felt the same as a hallucination without them freaking out?!

In late March 2016, I didn't know where to turn, but then I remembered a particularly friendly Pharmacist at my local chemist. I dropped in there one afternoon and asked him if he knew if the dose of my medication was known to cause people to see, feel and hear things that weren't there? He looked up all the information about my medication, and asked me lots of questions. After a long conversation, he told me he didn't think it was to do with my medication, and that it might be something more serious, and I should see a Doctor urgently. He even recommended a Doctor in the local area who was good.

I made an appointment to see this new doctor for early April 2016. I was nervous, having never met him before, I would have to tell him everything that was happening, and open up to this complete stranger. After hearing what I had to say, he was obviously concerned, and sent me to the Psychiatric Emergency Department at the hospital for an emergency review by the on-call Psychiatrist.

The on-call Psychiatrist also didn't feel it was an issue with my medication, but perhaps an episode of psychosis or some other issue. He referred me to the local Mental Health Out Patient Acute Care Team for further investigation and monitoring.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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The Psychiatrist from the Acute Care Team went through my entire medical history. He asked me lots of questions about any family or personal history of tumours. I told him that my mother had a benign brain tumour when I was a teenager, and that I had a benign teratoma removed from my right ovary in 2014. By his line of questioning, I assumed he thought I had brain tumour. And even though I thought he was thinking I had a brain tumour, this didn't faze or worry me at all. It was like he was asking me what my favourite colour was. It was such a non-event in my head somehow.

At the next appointment with the Psychiatrist he recommended withdrawing off my old medication and changing from an anti-depressant to an anti-psychotic. He said he wasn't sure what was causing it yet, but if it was an episode of psychosis, then I needed a different type of medication to help control it. He also explained that Borderline Personality Disorder was better managed with anti-psychotics, instead of anti-depressants. He also wanted me to get a specific blood test done at the hospital to check for some illness I had never heard of, that was associated with Teratoma tumours. I don't think either of us were convinced that I had this illness, but he wanted to rule it out, so I had the blood test.

As I knew how difficult the withdrawal and then adjustment period onto the new medication would be, I went on extended sick leave from work.

While I was waiting for results of the blood test, I started the horrible withdrawal process. In that time, I picked an almighty fight with my husband, kicked a chair, lost my balance and face-planted a tiled floor splitting my eyebrow open. I also attempted to carry a 2 seater couch up a narrow but steep stair case on my own, dropped it and broke my big toe. I am sure there are plenty of other stupid things I did in that time, but my memory from that period is very fuzzy.

After withdrawing fully off my old medication, I was slowly weaned onto the new anti-psychotic medication. The withdrawal was hard. A week after starting the new medication I started having a bad reaction, so had to change to another type of anti-psychotic medication. Luckily, this went smoothly, and very quickly I started to feel that all the symptoms of Borderline Personality Disorder started to be under control.

On the 3<sup>rd</sup> of May 2016 my blood test came back and it was positive for Anti-NMDA Receptor Antibodies. The psychiatrist confirmed that what I had been experiencing was an illness called Anti-NMDA Receptor Encephalitis (a type of inflammation of the brain caused by rogue antibodies that were developed to fight the tumour, but were now attacking my brain by mistake).

He didn't seem too worried about it at the time, but made it very clear that if my symptoms got any worse at all, that I was to go straight to the Emergency Department and tell them I had Anti-NMDA Receptor Encephalitis. He told me that this illness can progress very quickly and seriously. He referred me to see a Neurologist at the hospital for consultation and treatment.

Other than the hallucinations, and bizarre behaviour, I didn't actually feel sick. But here I was being told that something was attacking my brain because it had confused my brain with a tumour.

I had heard of encephalitis before, but couldn't really remember much about it. I was pretty sure it was treatable, but also pretty sure it could kill people. Then my husband told me that a character on the TV series Hannibal which we had just finished watching had encephalitis. That was our only frame of reference. In a way this was great for me, as it meant that when I finally told my husband about some of my symptoms including the hallucinations, he wasn't so shocked as he had watched the character on TV go through the same thing, and it almost became a bit of a joke.

Over the next few days I did a little research into this bizarre illness I was told I had. I am guessing the psychiatrist didn't want to tell me too much about it, because he knew I wasn't stable and didn't want to cause extra stress and anxiety.

At first it was very difficult to get any sort of answers about this illness. There were various medical research papers on this illness, but they all seemed to be slightly different in prognosis and treatment options. I found that this illness had only been discovered in 2009, and was considered rare, and was often misdiagnosed as psychosis or other mental health issues, or not diagnosed at all causing the patient to die from lack of treatment. I found that there wasn't a huge amount of research because it was so new and so few people had been diagnosed.

After reading a few articles, I found that the treatment that seemed to be the most popular was IV Plasma infusions, IV Steroids, and possibly chemotherapy.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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I learned that treatment and recovery could take months or even years! I learned that there is a high chance of continuous relapses, and that some patients do die from this. I learned that after experiencing psychiatric symptoms, the illness would progress into physical symptoms including not being able to talk or control my limbs, or seizures or maybe even slipping into a coma.

Despite all the scary information I was reading, I didn't feel sick, and it didn't actually bother me or scare me that much. My encephalitis clouded brain was obviously overriding normal emotions and reactions, although I didn't realise that was what was happening at the time.

After it had sunken in a little more, I had to sit my husband down and tell him how serious this illness was, that it could kill me, or I could slip into a coma. It could make me unable to control my limbs, or talk. I told him the treatment involved plasma infusions. It was a very difficult conversation to have, because I wasn't feeling worried or scared because my brain wasn't reacting normally, but the more I told my husband the more fear I could see come over his face. After talking about it for a little while he told me he needed to go and process the information. This is something he only does when he is stressed, angry, worried or scared. Yet it still didn't seem scary to me. It didn't seem serious, even though I had read about how serious and life-threatening it was.

I then had to tell my family what was happening. I needed all the people in my life to learn all about this illness and to know what to look out for, as there was a chance I wouldn't even notice if I started having worsening symptoms, or I may be unable to tell anyone that I am having issues.

Over the next few days, my friend who was living with us, my family and my husband all started telling me that my speech was slurred and really slowed down compared too normal. I thought perhaps it was either my new anti-psychotic medication or the pain killers. But it did appear to be getting worse. I was also noticing that my memory and ability to concentrate had gotten a lot worse, but I didn't tell anyone.

While I was waiting for the appointment with the neurologist, I was sent for an ultrasound to check for signs of another teratoma. There was no tumour, but they found 2 gall stones and 1 kidney stone, so I was referred for consultation with a general surgeon.

I had the ultrasound in the morning of the 12<sup>th</sup> of May 2016, 9 days after being diagnosed with Anti-NMDA Receptor Encephalitis. I was feeling fine in the morning. In the afternoon my friend and I went grocery shopping, and just as we got to the check-out I started to feel really strange. I felt like I was going to fall asleep on my feet, my eyes were closing, I couldn't stand up properly and I was having difficulty breathing. We rushed to get the groceries in the car and on the 20-minute drive home I got worse. I couldn't keep my eyes open, I couldn't take a deep breath, and I couldn't swallow – I felt like I was choking. When we pulled into the driveway, my friend half-carried me out of the car into the garage and sat me down on the armchair. I couldn't explain to my husband or friend how I was feeling. I couldn't figure out what words to use. After a little while I managed to get up and change into my pyjamas. But then it got worse again. I snapped at my husband for talking to me because I couldn't talk properly or figure out what words to use. My husband asked if I was ok, and I must have said yes, because he left to play darts. About 20 minutes later I asked my friend to call an ambulance because I was really struggling to breathe or swallow, it felt like something was stuck in my throat.

My friend hurriedly packed me an overnight bag, and soon the ambulance arrived. I don't really remember them arriving, but I remember talking to the paramedic in the back of the ambulance. I remember that my blood pressure was 110/60 and my pulse was 75bpm.

When we arrived at emergency I was assessed by a doctor who noticed that my temperature would randomly spike up, which was followed by another episode of feeling like I was going to black out, and then my blood pressure would crash. I told the doctor that I had been recently diagnosed with Anti-NMDA Receptor Encephalitis, and had just changed medication for Borderline Personality Disorder. They ran lots of tests, most of which were perfectly normal. They were testing my reflexes and that is when I realised that it had been weeks since I was last able to feel my left hand or either foot properly. It was like they were hollow.

The head doctor turned to the student doctors and said "I think she is making it up. Her symptoms don't make sense, and there is no obvious cause for the symptoms she is having." I was shocked by what she had said. Then one of the student doctors said to her "you do realise she has anti-nmda receptor encephalitis, so these symptoms make sense". They ran more tests and then moved me to a bed in a ward for further monitoring.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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The next day they told me they were going to get a Neurologist to come and see me to discuss treatment, but they wanted to run more tests including a lumbar puncture before that. They told me that I was possibly going to be in hospital for a few weeks. I called my mum and asked her to fly up from Sydney to be with me while I was in hospital and help out at home while I was stuck in hospital.

My symptoms came and went, got less and then increased again. They were all over the place. There was no real pattern or consistency. The doctors and nurses were totally baffled. I was being monitored closely and frequently.

I had a barrage of blood tests which were all normal, an EEG brain scan which was unremarkable, and an MRI of my brain which was also normal.

I had the lumbar puncture, which took them 6 goes to get the needle in. 2 days wait for results and it re-confirmed Anti-NMDA Receptor Encephalitis.

When the doctor who had seen me in emergency and accused me of making it up came to give me the results of the lumbar puncture she said to me "so it turns out you're not just crazy". I don't think I've ever been so offended. I was annoyed that it had taken them almost a full week to diagnose me with something I had been diagnosed with 9 days before arriving in hospital.

I finally saw the neurologist and he didn't seem too concerned as my symptoms were considered mild for this illness. He explained that I would be having 3 days of IV Steroids and 5 days of IV Plasma infusions. He explained that treatment often will bring on the symptoms more severely, but this was perfectly normal.

I was seen by nutritionists and speech pathologists and various other doctors. The nutritionist had been told to put me on a high-calorie diet as I needed to get my weight up before I could start treatment. I consumed possibly every pudding, custard, cake and biscuit in the hospital, and managed to get my weight above 50kg.

The speech pathologist told me that my speech was slurred, and I had difficulty with reading some words aloud, but she didn't think my speech was that slow. I explained that normally I speak faster than the speed of light, and now I sounded like a sloth! She also checked my ability to swallow, which worked fine when there was food or drink in my mouth, but as soon as my mouth was empty and I tried to swallow it felt like my tongue was stuck in my throat.

I saw a physiotherapist who assessed my mobility and ability to walk around, shower and toilet myself. She was happy with how I was moving, despite having no feeling in my feet and a broken toe.

I saw a psychiatrist who had the personality of a spoon, who rattled off a list of questions which didn't seem to make any sense to me, and she never gave me her opinion or verdict.

The thing that all the doctors and nurses were most worried about was how low my blood pressure was, and how it got significantly lower while I was asleep (as low as 90/40). And despite having such low blood pressure for as long as I can remember I have never had any issues with it, or felt faint or anything. In fact, the only time I am even aware of it is when I am in hospital and they keep panicking. They had to get special permission from the head doctor to not call him when my blood pressure dropped below 100/60.

In that first week in hospital my symptoms seemed to come and go, but I was generally well enough and mobile enough to go for walks around the hospital, or out to the garden out the front. I made friends with two of the most awesome women I've ever met who were sharing my ward, and chatted away to them like we were out having coffee like normal people. It was totally surreal to feel so fine despite having a life-threatening illness.

After a week in hospital being poked, prodded, tested, drained of vials of blood and various other bodily fluids, and seeing what felt like millions of doctors I was told that they would start the treatment on the following Monday. I got really upset that I was going to be trapped in hospital all weekend if nothing was happening. They gave me leave pass to head home for the day on both Saturday and Sunday, but I had to be back in my hospital bed by 8pm both nights.

The weekend I was allowed home I remember crying when I saw my dog when I got home on the Saturday, but that is the only thing I remember about the whole weekend. I think I did washing?

When I got back to the hospital on Sunday night I was suddenly overcome by intense fear about treatment starting tomorrow. And fear about the possibility of symptoms coming on worse than before. I couldn't stop crying. A few years ago, when I was recovering from my tumour removal surgery, my sister had sent me a "box of sunshine" which was a whole lot of little gifts that were all yellow, to cheer me up and spread sunshine in my life. One of the gifts was

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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yellow nail polish, because you can't possibly be sad with yellow toe-nails. So sometime around 9 or 10pm, I went outside and sat on the grass out the front of the hospital, in my pyjamas (that I had bought from the boys' kids section at K-mart), bawling my eyes out, sitting in the dark painting my toe-nails yellow. I was sitting there thinking how odd it must look, and how I could possibly explain to security guards that I hadn't escaped from the psychiatric ward if they came and talked to me! I believe that life is constantly cracking jokes, you just have to wait and look for them. Right at that moment, a drunk man came running out of emergency with no pants on, chased by a nurse and 2 cops. He was yelling "you will never catch me; you will never make me put on my undies!!" It made me laugh so hard. I stopped crying. I did a terrible job of painting my toe-nails in the dark by the way, especially considering one toe-nail was black from where I broke it, and the other had a big slice mark across it from when I attacked it with a knife.

I didn't get much sleep that night.

On the Monday I had yet more blood tests. They didn't start my treatment till around 2pm. The wait was not doing anything for my nerves and fears - I just barely managed to keep it together.

First was 2 hours of IV steroids. That was really tough. People with mental health issues such as Borderline Personality Disorder often feel that steroids gives them the feeling of a panic attack. I had previously had a panic attack when taking steroids for a throat infection, so I was expecting the worst. What they didn't warn me is that it would give me the most horrible taste in my mouth. And because it felt like a panic attack I was trying to take big slow breaths to calm myself down, but every time I did the taste in my mouth was unbearable, so I kept holding my breath or shallow breathing which made it feel worse. The panic attack feeling lasted the whole 2 hours the IV was in, plus about half an hour after it was finished. When that was finally finished I needed to go for a walk and de-stress.

Then they started the IV Plasma infusion. They have to start the drip very slowly to start with, and increase the flow slowly every half hour, and before they increase the dose they check your blood pressure, pulse and temperature every time. It took almost 5 hours for the first plasma infusion. I didn't experience any side-effects or feel anything other than a bit fidgety at having to sit still for that long, not able to really do anything.

It was around 9pm when they finally finished my treatment! My darling mother had sat by my side the whole time, supporting me and chatting me to keep me entertained. When they finally finished I could see that she was exhausted. I walked her down to the taxi rank and put her in a cab home.

I walked around for a while in the garden, stretching my legs. I slept like a baby that night.

The next day I went to the shop and bought some lollies to suck on while I had the steroids. I was prepared this time. And while it didn't do anything for the 2 + hour panic attack feeling, at least I didn't have the terrible taste and could breathe normally. After 2 hours, I was un-hooked and went for a walk to stretch out a bit.

Then IV Plasma. Because I had handled it so well the previous day, they were able to speed it up a little, so it only took 4 hours.

Day 3 of treatment, more steroids and IV plasma. On this day, halfway through my plasma infusion I turned to my mum and said "oh my god I can feel my feet! But now I can feel my broken toe!!!" It was such a strange sensation to get feeling back in your feet after weeks of not feeling them. My mum reached down and touched my foot and said "WOW they are warm! Your feet have never been warm a single day in your life!" I had been living in big fluffy bed-socks for months because my feet were like icicles! We both giggled about how excited we had gotten about the fact that I could feel my feet and they were warm.

Day 4 and 5 of treatment was just IV Plasma, no more steroids. Such a relief.

The Neurologist came to see me and asked me if I planned on having any children, and if so when. I was a little taken back. He explained that they recommended I had 2 rounds of a type of chemotherapy every 6 months to help prevent relapse. If I wanted to fall pregnant, I would have to stop the chemotherapy treatment for 12 months before trying, and then couldn't start again till after breast feeding. There was some risk of relapse by stopping the chemotherapy for that length of time. What he didn't realise is that was a sensitive subject, as I wasn't even sure if I could have children without IVF due to the scarring from the previous tumour removal surgery. Plus, we were not in a situation to be ready to have a child right now. He told me I needed to make a decision about choosing to have a child straight away, then starting chemotherapy, or starting chemotherapy and then stopping to have a baby. He also told me there was some risk that the chemotherapy would affect my fertility. It felt like a slap in the face. I called my husband and

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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we talked about it. I felt like I couldn't make a decision without knowing if I was even able to have a child. And I was half way through treatment for a life-threatening illness, having a baby wasn't on my mind at all, just surviving was!

After finishing my final plasma infusion, they told me they needed me to wait for an hour or so, so they could monitor me, but then I could go home! They warned me that I could get headaches and feel a bit tired over the next few days, but it shouldn't be too bad. They arrange a referral to the gynaecologist for fertility testing before I would make the decision whether I would go ahead with the chemotherapy or not.

I was finally discharged after a little over 2 weeks in hospital.

I remember getting my discharge report from the Doctor, but I don't remember leaving the hospital or getting home.

The next day I woke up with an excruciating headache and a temperature. I barely moved off the couch the whole day. I also had lots of blood in my nose.

It was the same the next day as well.

The next day I went to see my GP for follow up. He told me the nose bleed was from the blood thinners I was given before they started the plasma and not to worry. The headache was also normal, but if it didn't resolve soon or became too much to handle I would need to go back to hospital. Then he checked my blood pressure and pulse. My pulse was 122 beats per minute, while resting, having done nothing but lay on the couch for 2 days. He was very worried. He wanted me to go back to hospital. I lost it. I burst into tears. I couldn't face the idea of going back after just being released. I asked him to phone my neurologist to see if he was worried about my pulse. While he did that, I sat outside in the gutter and cried my eyes out. I called my husband and asked him to come home early from work. My doctor came and told me that if it didn't settle down in a few hours I would have to go back to hospital, but I needed to get it down to below 110 bpm.

I went home, still in tears. When my husband got home he bundled me on the couch, wrapped me in a blanket and stroked my hair while I drifted in and out of sleep. Mum periodically checked my pulse. All three of us were glued to the couch for the rest of the day and into the evening. Neither of them left my side. Eventually my pulse started to slow down, and dropped below 110 bpm.

The next few days are a blur. I am not sure I did anything other than lay on the couch and nap. Mum was looking after me, bringing me food and water and checking my pulse.

After a few days, I was feeling a little stronger, so my mum flew home.

The first few days at home alone was a bit tough. Husband at work, mum gone home. Just me and my dog. I didn't do much. Lots of couch and TV.

While I was in hospital my friend decided she couldn't handle it and moved out. This put a huge strain on us financially. Especially as I had already been off work for over a month. And now the huge house felt so empty.

The next few weeks are also a bit of a blur. But at some point in there I had my fertility testing done. There was no issue with delaying pregnancy for a couple of years, and they put a plan in place for IVF to speed up the process if needed.

I saw my Neurologist for my 1 month review. I told him I was still unsure about having chemotherapy because I was concerned about side-effects, but that my fertility issues weren't a factor. He said that some studies show that chemotherapy reduces chance of relapse from 25% down to 10%, and the side effects weren't too bad as it was a mild dose, it would feel like I had the flu for 4-6 weeks at worst. I reluctantly agreed. He booked me in to have 2 doses spaced 2 weeks apart.

My mum came up for my chemotherapy treatments, even though they were only half day treatments. They gave me an antihistamine beforehand, as there was a high instance of allergic reaction to it. This was a blessing in disguise, as it made me so doopey I slept through the whole thing.

The next few days were pretty rough. Horrible upset stomach, headaches, nausea, vomiting, lethargy. I felt like I had been hit by a bus, while having the flu! These symptoms lasted for days, and didn't seem to get any better.

2 weeks later I had my 2<sup>nd</sup> chemotherapy treatment, which again I slept through. And after the second dose, I was feeling worse than ever.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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I felt sick in every way imaginable for the next few weeks. It was so bizarre that when I was first sick I didn't feel sick at all, and now the treatment that saved my life was making me feel terrible.

I was still having some symptoms of encephalitis, but the hallucinations had stopped, my speech was back to normal. My memory and concentration and decision making skills were still nowhere near what they were before I got sick. This was the hardest part to adapt to.

I was getting ready to return to work after over 4 months off work. When I contacted my work, they made it impossible for me to return. They told me I needed to get clearance from their nominated doctor. I wasn't sure they would pass me, as I still had symptoms, and had a high chance of relapse. I got a clearance certificate from my GP but my work wouldn't accept it. I had no choice but to try and find a new job, while feeling terrible, knowing I wasn't 100% and that my brain was still struggling.

I had a job interview, and told them about my illness. The manager's brother-in-law had a type of encephalitis, so he knew what I was going through. Somehow, I managed to impress him enough and got offered the job. They gave me an extra 2 weeks to recover before starting.

I started working at my new job mid-August 2016. It was really tough. I was nauseous every day. I had no energy. And the worst part for me was that I knew my brain wasn't 100%. I struggled through as best I could, but felt that my boss was looking for a reason to get rid of me not long after I started.

Over the next few months I became totally obsessed with finding answers to all the questions I had about this illness, but it didn't matter how much I researched, I couldn't find answers to any of my questions. I wanted to know how long I would feel sick. I wanted to know how I would know if I was relapsing. I wanted to know so many things.

I have always been one of those people who has to know everything. If I don't know the answer to something, I go out and research it until I become an expert on the subject, even if I never need the information ever again. I love watching documentaries, and reading research papers. I feel totally uncomfortable when I don't know everything.

I was being reviewed every 4-6 weeks by my Psychiatrist, who was monitoring me for signs of Borderline Personality Disorder flare ups, as well as signs of encephalitis relapse.

I seemed to be doing ok, despite still having a lot of symptoms, and feeling sick every day. I ended up in emergency a couple of times, for fast heart rate, heart palpitations and chest pains, but they couldn't find anything.

Then by November, my obsession for answers about Anti-NMDA Receptor Encephalitis got worse. I became all consumed. I was working myself up into a panic attack when I couldn't find answers, what had started as a way to make my mind feel calmer, ended up making me feel so much more stressed and panicked. Then I started reading other people's stories, and the horrors they went through that was so much worse than mine, and I felt guilty for not being as bad as them.

I couldn't find a single other case of someone developing encephalitis after their teratoma was removed, and without having a second teratoma. I never had symptoms of encephalitis while I still had the teratoma, or the period immediately after it was removed. I had no symptoms for almost 2.5 years. Then I developed encephalitis. The antibodies must have been in my system the whole time, but never attacked my brain until 2.5 years later. I couldn't find a single other case that was remotely similar. There are cases of people developing the encephalitis without the teratoma ever being found, but none who developed it after the removal of a teratoma. There is a lot of information that says the patients who recover the fastest and best are those that have the teratoma removed as part of their treatment. I had my teratoma removed, then 2.5 years later got sick?

I started a spreadsheet to keep track of all my questions. It ended up being 8 A4 pages long. I took this with me to my next appointment with my Psychiatrist. He was concerned. He said my behaviour was bizarre. I was having more symptoms. My short term memory was getting worse. He wasn't sure, but he thought perhaps I was relapsing. He suggested I get a second opinion from a Neuro-immunologist that I had heard about through an Anti-NMDA Receptor Encephalitis Support page on Facebook. He also said I should see my neurologist again urgently for review. I had an appointment already scheduled with my neurologist for the following week.

That week at work, I had a meeting with my boss about my continuing issues with my health. A week later they came up with an excuse and fired me. It was the day before I was to see the Neurologist for answers.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

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I saw the neurologist, and he was very concerned about my increase in symptoms, and agreed that I was showing signs of relapsing. He wanted me to be admitted to hospital urgently for another 5 days of plasma. He also wanted to talk to another specialist about how many side effects I was having from the chemotherapy, and the possibility of stopping that altogether. I was booked in for admission 4 days later.

The few days leading up to going back into hospital was really tough. I was cleaning, and washing, and cooking food to put in the freezer so my husband had something to eat while I was in hospital. I suddenly was overcome by the feeling that I was preparing things in case I died! I cried a lot. I was so scared. This time was different. I had slightly more control over my brain so was more aware of what was happening. Plus, this time, I had time to prepare, which meant time to think, last time I ended up going in by ambulance. I was consumed by the fear of dying and leaving my husband and dog behind. I tried to keep my fear hidden from my husband as I didn't want to worry him, but I'm sure he knew I was scared.

On 7/12/2016 I was admitted to hospital again for 5 days of plasma treatment. No steroids this time. They also did a 48 hour heart monitor, and took more bodily fluid samples. They found that at some point I had picked up some particularly nasty bacteria, which required antibiotics. This time the crazy intense pressure headache started on day 3 of treatment. I spent a lot of time drugged up on strong pain killers with an icepack on my head. The headache got so bad it made me vomit a couple of times.

After a quick 6 day visit, I was discharged from hospital again. I am still waiting to see the neuro-immunologist, waiting for a scan of my heart and results from 48 hour monitor, and waiting to find out if I need chemotherapy again.

The pressure headache lasted 5 days this time, then stopped for a few days and then came back for a few days. I have also got the worst upset stomach again, worse than last time – everything I eat goes straight through me. I am still waiting for test results to see if maybe the antibiotics didn't quite clear up bacteria.

I am still waiting to see the general surgeon about the gallstones, but I am not sure how it will work with having a general anaesthetic, as the part of the brain that is affected by the anaesthetic is the NMDA receptors. I am worried that if they knock that area out, and it's not recovered enough, that I may not wake up again. Or it might make encephalitis come back. Or might make things worse.

I am without a job again. And in no condition to try and find a new job, let alone start one. I also have so many specialist appointments that I am waiting for.

Christmas was again ruined by my health. I couldn't last the whole day at the family gathering, and got serious pains in my stomach when I tried to eat.

Despite having had diarrhoea and vomiting for the last 5 months straight, I have managed to gain weight and am now 57kg (which is the heaviest I've ever been, other than when I had the tumour). The great irony is that people who see me think I look great as I've gained weight, they assume that means I'm feeling well. And just for another encephalitis-related-kick-in-the-teeth, back in March in the height of my encephalitis crazy behaviour, for the first time in my life I cleaned out my wardrobe. I got rid of all the clothes that were too big for me (8 garbage bags full). I didn't realise how skinny I had gotten, or that my skinniness was because I was sick. Now that I am nice and plump, none of my clothes fit, and I am living in stretch pants and pyjamas, and because I have been off work for so much time, I can't justify spending money on new clothes!

This year has been totally bizarre. Big chunks of time are completely gone from my memory, or I remember things totally different to how they actually occurred, or in a different order to how they happened. I have lost 2 jobs due to ongoing issues with my health. And the life-saving treatment I keep receiving, actually makes me feel worse, which is a sign it is working? (I hope).

I am sure there is a lot that I have missed from my story, but they have simply vanished into the abyss of encephalitis.

The worst part, for me, has been losing confidence in my own brain, I no longer trust anything it is doing. When I hear a noise, or see something moving, I question if it is real or another hallucination. When I make a decision, or try to, I don't trust that it is the right one. When I try to remember things, I am not sure if it is correct.

And the most difficult thing to come to terms with is the enormous guilt I feel for the emotional and financial strain I have caused to my husband and family, all because my own immune system is trying to kill me. I know it is not my fault, but it is my body that has caused the problem.

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

It has been around 2 weeks since I got out of hospital this time, and I am feeling weak and sick every day. I can't eat much, as I get pains in my stomach followed by diarrhoea or nausea. The pressure in my head feels like my sinus is blocked, and makes me a bit deaf. I get confused easily, and it takes me a long time to get my thoughts together enough to carry out basic tasks.

And just before Christmas, when I was walking up my driveway, I saw a large fluffy border-collie dog run across my yard. I looked for it for about 5 minutes until my husband asked me what I was doing. Then I realised it wasn't there. And I've been hearing loud crash-bang noises in other rooms of the house, but nothing is ever out of place. Oh and I can't stop salivating, to the point where I keep accidentally drooling on things!

I've been keeping pretty positive throughout this whole ordeal, but there comes a point when you are just so sick of fighting against the illness and its never-ending merry-go-round of bizarre symptoms!

I feel lucky that throughout this whole process I have remained conscious, and been able to communicate how I was feeling most of the time. I have maintained enough brain function to be able to research and keep records of my symptoms, and write this story of my journey. I am lucky that my case was very mild.

Never in my life have I ever been described as "Normal". But right now, after the year I've had, I would love nothing more than to be told "you are normal"!

I am determined to kick this illness out of my body for good, I just need a nap first!

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*Below I have listed my symptoms at various stages of my Anti-NMDA Receptor Encephalitis journey.*

<b>MY SYMPTOMS PRIOR TO DIAGNOSIS AND TREATMENT FOR ANTI-NMDA RECEPTOR ENCEPHALITIS (FROM DECEMBER 2015 - APRIL 2016)</b>	
Fevers	Lisping
Nausea	Slowed speech
Diarrhoea	Erratic sleep pattern – days of insomnia and days of over sleeping
Paranoia	Visual and auditory hallucinations
Sensory hallucinations	Short term memory loss
Memory deficits	Abnormal swallowing / difficulty swallowing
Feeling of something stuck in throat	Clearing throat / coughing constantly
Pressure in head	Loss of appetite
Weight loss – down to 38kg	Confused thinking
Episodes of blacking out / fainting	Increased temper and verbal violent outbursts
Difficulty taking deep breath	Lethargic
Sporadic spikes in temperature, followed by feeling like passing out	Numbness in hands and feet – feet were very cold

<b>MY SYMPTOMS POST 1<sup>ST</sup> ROUND TREATMENT</b>		
<i>1<sup>ST</sup> LINE TREATMENT: IV METHYLPREDNISONE 1G X 3 DAYS &amp; 0.4G/KG IVIG X 5 DAYS (MAY 2016)</i>		
<i>2<sup>ND</sup> LINE TREATMENT: RITUXIMAB X 2 DOSES (JULY &amp; AUGUST 2016)</i>		
SYMPTOM / SIDE EFFECT	FREQUENCY	WHEN DID IT START
<b>Racing heart</b> – average 90-110 BPM (has spiked as high as 135)	4+ days per week sporadically, for periods of time 1+ hour resulted in 1 x trip to emergency and multiple trips to Doctor	First time noticed was 3 days after discharge from hospital
<b>Chest pain with no specific origin</b> - all tests negative / clear / normal	Has happened twice, and resulted in 1 trip to emergency	Started October 2016
<b>Short term memory loss</b> - this was one of my symptoms of encephalitis	at least once per day, some days worse than others	started when the encephalitis started, and has not changed post treatment
<b>Diarrhoea</b> within an hour after eating	8/10 times after eating	This started after 1st Rituximab treatment

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

<b>Pain in my abdomen / digestive system / lower intestine after eating</b>	8/10 times I eat proper / large meal, but doesn't happen if I eat a small snack	This started after 1st Rituximab treatment
<b>Nausea and/or vomiting</b>	is starting to settle, still maybe 1-2 times per week	This started after 1st Rituximab treatment
<b>Urge to put things / food in my mouth and/or chew</b>	Every day. Some days it is so bad I eat 3-4 times what I normally would, and can't get rid of the urge/craving feeling.	started when the encephalitis started, and has not changed post treatment
<b>Feeling like there is something in the back of my throat or tickling the back of my throat</b> - I find myself trying to clear my throat for periods of over an hour trying to get rid of the feeling	10+ times per week	this started when the encephalitis started, and has not changed post treatment.
<b>Weird swallowing habit</b> – like trying to bring something up from the back of my tongue to front of mouth repeatedly, until I can feel saliva on the front of my tongue, then swallowing. This is causing the roof of my mouth to feel strange.	every day, some days worse than others	this started when the encephalitis started, and has not changed post treatment.
<b>Uncontrollable Specific food cravings</b> - usually sweet or salty - cravings for a specific item can last anywhere from a few hours to days - cravings don't always go away after eating the specific item - has gotten so bad once that I drove to woollies at 9pm in my pyjamas to buy 5 packets of a specific biscuit because I couldn't sleep until I had them, and then I got home and couldn't actually remember the drive or going into the shop, but was aware that I had done it	2-3 times per week	started when the encephalitis started, and has not changed post treatment.
<b>Nose-bleeds (not bad ones)</b>	1-2 times per week	Started post treatment
<b>Blocked sinus</b>	Every day, worse at night	Started post treatment.
<b>Waking up with lots of dry blood in my nose but no blood anywhere else</b>	1-2 per week	Started post treatment
<b>Snoring - was not a snorer previously</b>	Most days?	Started post treatment
<b>Confusion</b> – difficulty processing complex information or solving problems	3-5 times per week	started when the encephalitis started, and has not changed post treatment
<b>High temperature</b> - with no other symptoms – above 37°C	this has happened a few times and lasts 3-4 days each time	Post rituximab
<b>Lisping when talking, or mispronouncing words</b>	2-3 times per week. Is worse when I'm tired	this was one of my symptoms of encephalitis but was constant for about 8 weeks before treatment, and then resolved post treatment. Now it only happens on-and-off.
<b>Difficulty making decisions</b> – I am not sure if this is because I get confused, or if it is because I have lost a lot of self-confidence and am now second-guessing everything my brain does	Every day	This started with encephalitis, but seems to be getting worse (probably due to confidence issue)

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

<b>Excessive sweating</b> - with or without a high temperature	(3-4 times per week)	Post rituximab
<b>Pins &amp; Needles/numbness in feet</b>	2-3 times per week	this was one of my symptoms of encephalitis, but was constant for 4+ weeks prior to treatment, and then resolved post treatment. Now it only happens on-and-off.
<b>Lethargy / physical exhaustion</b> - gets to a point where I feel like I am too tired to talk or breath - physically exhausted but mind still active	1-2 times per week	This started when I was in hospital for encephalitis. Appears to be getting less frequent.
<b>Generally feeling run down</b>	Every day	This started with encephalitis
<b>Can't eat at all / no appetite / eating makes me feel like gagging</b>	1-2 times per week	This started with encephalitis
<b>Temperatures up to 39.2 without feeling like I am hot, no sweating, no other symptom associated, lasts anywhere from 20mins to 1.5 hours</b>	Daily	Started October 2016

### MY SYMPTOMS 1<sup>ST</sup> RELAPSE (NOVEMBER / DECEMBER 2016)

SYMPTOM / SIDE EFFECT	FREQUENCY	WHEN DID IT START
<b>Racing heart</b> – average 90-110 BPM (has spiked as high as 135)	4+ days per week sporadically, for periods of time 1+ hour resulted in 1 x trip to emergency and multiple trips to Doctor	First time noticed was 3 days after discharge from hospital after 1 <sup>st</sup> round of treatment
<b>Short term memory loss</b> - this was one of my symptoms of encephalitis	at least once per day, some days worse than others	started when the encephalitis started, and has not changed post treatment
<b>Diarrhoea</b> within an hour after eating	8/10 times after eating	This started after 1st Rituximab treatment
<b>Pain in my abdomen / digestive system / lower intestine after eating</b>	8/10 times I eat proper / large meal, but doesn't happen if I eat a small snack	This started after 1st Rituximab treatment
<b>Nausea and/or vomiting</b>	is starting to settle, still maybe 1-2 times per week	This started after 1st Rituximab treatment
<b>Bad Nose-bleeds</b>	1-2 times per day	Lasted for 2.5 weeks in November 2016
<b>Excessive salivating</b>	Every day	Started in November 2016
<b>Weird swallowing habit</b> – like trying to bring something up from the back of my tongue to front of mouth repeatedly, until I can feel saliva on the front of my tongue, then swallowing. This is causing the roof of my mouth to feel strange.	every day, some days worse than others	this started when the encephalitis started, and has not changed post treatment.
<b>Confusion</b> – difficulty processing complex information or solving problems	3-5 times per week	started when the encephalitis started, and has not changed post treatment
<b>High temperature</b> - with no other symptoms – above 37°C - highest was 39.2 - I was not aware I was hot; it was pointed out to me by someone else	Every day for a few weeks	Started in October 2016
<b>Lisping when talking, or mispronouncing words</b>	2-3 times per week. Is worse when I'm tired	this was one of my symptoms of encephalitis but was constant for about 8 weeks before treatment, and then resolved post treatment. Started again in November 2016

## MY ANTI-NMDA RECEPTOR ENCEPHALITIS STORY

<b>Difficulty making decisions</b> – I am not sure if this is because I get confused, or if it is because I have lost a lot of self-confidence and am now second-guessing everything my brain does	Every day	This started with encephalitis, but seems to be getting worse
<b>Severe pressure headaches</b>	5 days post Plasma then went away for 3 days then returned for 4 days	Started on day 3 of plasma infusion

### MY SYMPTOMS POST TREATMENT FOR RELAPSE (DECEMBER 2016)

*5 X IVIG PLASMA INFUSIONS (DECEMBER 2016)*

SYMPTOM / SIDE EFFECT	FREQUENCY	WHEN DID IT START
<b>Racing heart</b> – average 90-110 BPM (has spiked as high as 135)	4+ days per week sporadically, for periods of time 1+ hour	Hasn't changed since treatment
<b>Had a few hallucinations</b>	3 times all on one day	Was after most recent plasma treatment
<b>Short term memory loss</b> - this was one of my symptoms of encephalitis	at least once per day, some days worse than others	started when the encephalitis started, and has not changed post treatment
<b>Diarrhoea</b> within an hour after eating	8/10 times after eating	This started after 1st Rituximab treatment
<b>Confusion</b> – difficulty processing complex information or solving problems	3-5 times per week	started when the encephalitis started, and has not changed post treatment
<b>High temperature</b> - with no other symptoms – above 37°C - highest was 39.2 - I was not aware I was hot; it was pointed out to me by someone else	Every day for a few weeks	Started in October 2016
<b>Confusion</b> – difficulty processing complex information or solving problems	3-5 times per week	started when the encephalitis started, and has not changed post treatment
<b>Excessive salivating</b>	Every day	Started in November 2016
<b>General exhaustion</b>	3 days per week	Has come and gone since Encephalitis started