I would like to dedicate this book to the people that got me through some incredibly dark times to where I am today. Loved ones, friends new and old, and also my incredible admins that manage our Facebook Migraine support group, Chloe, Gemma and Deborah. The ones behind the scenes working incredibly hard work to support others with this illness day in and day out.

**July the 31st 2015**

That’s the day my life changed forever. It’s like a line in a film isn’t it? I wish it was just a film and I could walk out of the cinema afterwards and realise, wow, that was intense, now back to my normal life!

But this was reality, and it hit me HARD!

If I had known then, how tremendously difficult and traumatic the years ahead of me would be to get me to where I am now, 5 years later, I honestly don’t know if I could have done it.

And to this day, my biggest fear is relapsing and going back to square one after I lost so much……. I’m sure yours is too.

In my personal life, I had a partner I was very content with and after a year together, things were progressing well. I also had a new job as an affiliate manager in a travel company called Cheapflights in central London. I was nearly 3 months in and only days away from my probation period - where the powers that be would decide whether to make me a permanent member of staff or not - and it’s fair to say stress was at an all time high during this period.

I often hear that it’s usually an intense period of stress that can be the major cause of triggering vestibular migraines or an illness, and I know at least in my case, this is what likely happened. Like it was lying dormant just waiting for all the right triggers and then BAM!

It was lunchtime and I was meeting my best friend in Russell square park close to the British Museum. It was a beautiful Summers day and as I weaved down bustling Goodge street, all of a sudden, I had what only can be described as a ‘spin out’.

Within a split second, everything around me spun around so intensely in a sort of half spin, that my eyes could not keep up and were dragging behind me. This was also met by a dizziness and disorientation so intense that it almost bowled me over and I desperately clung on to a nearby wall for dear life, waiting for it to pass whilst I swayed to and fro, trying to regain my balance. My top, I realised, was damp from perspiration and even in the balmy heat of June, I shivered in a cold sweat whilst it clung to my back.

It was terrifying, especially as I had NEVER experienced anything like this before, ( Which I would later understand to be a vertigo attack ) - but it started to subside so I carried on walking - albeit very slowly - to meet my friend in the park. I was late and I tried to convince myself it was a one off and tried to stay calm and ‘get on with it’ as we had always been taught in our family. Maybe it was a virus, the flu was going around in the office and a lot of people were off sick during this time.

( Important to mention here my dad was ex special forces in the marines and I swear this was both a blessing and a curse as I dealt with my recovery. On one end, I battled through like he would do, on the other, I was too hard on myself and pushed myself to the brink of exhaustion on a constant basis in the early months of my illness. A healthy balance of knowing when to push and when to rest is vital when it comes to recovery, I found with this illness )

I made my way to the park, the bright sunlight seemingly burning through my retinas and for some reason, they were sore and super sensitive.

I saw my friend and unsteadily made my way over to her and told her what had just happened. She told me there was a virus going around and it was probably just that and not to panich too much, so I headed back to the office, warily creeping past where the dizzy attack happened only 40 minutes earlier and made my way back to my desk where it was another 5 hours solid on the computer screen. I really struggled with the brightness and reading the word and as I scrolled it made me feel dizzier. Add to that double screens!

By the end of the day, I felt absolutely exhausted and something in my head just didn’t feel right. It was like I was slightly woozy and disorientated. I made my way home on the bustling tube and felt off balanced the whole way and slightly nauseous. By the time my partner had arrived back, I had already crashed out for the evening.

It will ease by tomorrow…….. I thought.

**The Next Day**

I woke up completely exhausted, like I hadn’t had an hours sleep even though I had slept deeply for at least 8 hours solid according to my partner. I dressed in a sluggish haze and applied my make up, all the while feeling a bit out of it and made my way to the kitchen to grab a cereal bar. Then I was out the door and on my way up Hammersmith road to get the tube.

I still felt a little unsteady and dizzy, like I couldn’t walk in a straight line very well and my balance seemed a little off, but I ignored it and jumped on the District line. As to be expected at this time in the morning, it was packed and I stood near one of the doors, swaying with the train and trying to keep my balance.

All of a sudden, I had a wave of nausea so strong I honestly thought I was going to be sick and it took everything I had to hold it until the next stop where I pushed passed people and launched myself out of the door and onto the platform, heaving and doing everything I could not to be sick in public. People were looking at me oddly and then the dizziness hit with a vengeance.

I grabbed onto the closest metal seat and sat down and waited for the nausea, dizziness and spinning to stop. I started to tear up in a panic, this was more than just a virus, I knew then and there something was very wrong.

I knew I would have to go straight home to bed and I called in sick. The train home was a COMPLETE nightmare. I was so dizzy, nauseous and everything was moving. The train was packed and there were no empty seats. I then tried to be rational and calm myself down convincing myself it HAD to be just a virus….. What else could cause these sudden spinning and nausea attacks?

I wobbled all the way down the street towards my house and it took everything I had to make it up the stairs. I crashed into my bed fully clothed and tried to shut my eyes, impossible. Everything was moving which led to more nausea. I felt like the bed was moving and it was rocking beneath me.

Do you know that feeling you get when just as you’re about to fall asleep and drift off into a dream, your body jumps and you wake up with your heart pounding? Exactly. I hardly slept that night, between mini spin outs and feeling like I was going to fall through the bed, I tossed restlessly holding back the tears and the panic. Surely once I’ve had a few hours sleep this will go?

**Day 2**

I open my eyes. It’s still there.

I can’t focus on anything and everything is moving. I have a really loud ringing in my ears, tinnitus. ( Tinnitus would continue to be the first thing I heard in the morning for the next 14 months, and depending on what day I was going to have, it would either be an unbelievably high shrill whistle, or a penetrating dull hum…… meaning potentially less symptoms that day. )

I call work and feel a lot of guilt and tell them I’m still sick. They’re understanding and tell me a virus is going around at work and to rest up.

I put the phone down, the whole room is moving. I am unable to focus on anything for more than a split second before it moves in front of me and I can’t work out how close things are to me, my spatial awareness is WAY off!

Now I'm really starting to panic, especially as I stand up and can hardly make it out the door to the bathroom. I use my shoulder pressed against the wall to guide me, gripping onto the door frame to pull me through to the bathroom. I realise I can’t do the simplest things. I can’t walk down the stairs, I have to sit on my backside and go down one step at a time. As for making tea? Forget it!

I feel too weak to hold the kettle to the tap and fill it up and as I go on my tiptoes to reach the top cupboard for the teabags, I lose my balance and slam my hip into the counter. I grab another cereal bar and crawl back up the stairs to my bed where I stay most of the day. I am so dizzy and nauseated I cannot even brush my hair. This carries on for a full WEEK before I call my doctor in desperation. She tells me I need to come in so she can check me out properly. This leads to another dizzy day from hell, but at least it’s not rush hour. I remember sitting in the waiting room whilst the people sitting opposite me move in a distorted way and the floor swirls in strange patterns.

I see a GP and tell her I’m extremely dizzy, I can’t focus on anything or do the simplest of things but she just sends me home to rest, certain it is a virus after I tell her that others in the office are off sick too.

I spend the next 2 weeks off sick from work, dizzy 24/7 with mini vertigo spin outs, laying on a moving bed, exhausted and tearful. I am so dizzy I cannot even watch T.V or read. This is a vicious cycle because I also cannot close my eyes as I feel my body drop through the bed and grab onto it wildly, then the tears come again. I can barely dress myself, makeup is a no go and as for washing my hair? Forget it. I did a half shampoo job but I was too weak to dry it with the hair dryer so I just went back to bed with a damp towel around it.

Would the symptoms lessen in the morning?

**August 2015**

I’m back at the doctors literally begging for help. It’s hard not to get tearful which makes it worse as she tells me it could just be stress and anxiety. This would be a pattern that would be repeated many times with many different doctors. When you live in London, there tends to be a lot of different doctors in the surgery and if you go to a walk in appointment in the mornings, it’s rare you get the same GP and they are so busy and stressed they don’t really have the time to go into all the details and past history of your case.

( As time went on, I became more assertive about my needs and an expert in my condition and refused to be fobbed off with just another ‘seizure medication’ for example. )

I was exasperated. I tell her NO! I am dizzy 24/7, for the last 2 weeks solid. I struggle to do the simplest things, like brushing my hair, applying makeup, even filling a kettle with water! This is NOT right!

Because I also had developed tinnitus during this period, she really did think it was just a very nasty virus that may have caused labyrinthitis. Labyrinthitis is an inner ear infection which affects your balance. It's sometimes called vestibular neuritis. It USUALLY gets better by itself within a few weeks. She ended up prescribing me a medication called stemetil.

Prochlorperazine belongs to a group of medicines called 'phenothiazines'. It is prescribed for a variety of unrelated conditions, including problems with balance and dizziness, sickness (nausea and vomiting), agitation and restlessness, and schizophrenia. Prochlorperazine is thought to work by blocking the action of a chemical called dopamine which acts on the nervous system in the brain.

To say I was ecstatic was to say the least. I now had a diagnosis and more importantly medication to help with the dizziness. Little did I know then that it was actually Vestibular migraines and it would take another YEAR to be correctly diagnosed. The issue is not always the doctors fault. There are literally HUNDREDS of conditions that cause dizziness. It would be very hard for an overworked London doctor to get it right and seeing as I had a virus that caused dizziness and she had treated others with labyrinthitis, it seemed a logical explanation.

So DID Stemitil help? In the early days it would take the edge of slightly for around 4 hours tops. At least this was enough to help me get the train to doctors appointments and cross roads when I had to do food shopping, but it was not a permanent cure for my symptoms. Everything still jumped around and I still could not focus on anything for too long.

**September to November 2015 -The Fight**

I wake up, I look at the ceiling above me, it moves and I feel a gentle rocking beneath me, as if the bed is moving…… I hear the loud ringing in my right ear. I know instantly it’s going to be a bad day.

I feel completely spaced out, like I’m not really present, like I’m in a dream but this is not a dream...... it's a complete nightmare. I want to cry but I know I can't. The headaches will start and I will feel dizzier. ( I think this was an early sign of the migraines but to begin with they were mostly silent.) HOW is this possible? To be dizzy 24/7 for weeks??? SURELY it has to go soon?

I depressed myself the last few weeks by googling my symptoms. People have had labyrinthitis for YEARS! And the Facebook groups don’t offer much help either! All tales of woe and desperation.

I found that Googling is both a blessing and a curse. The good thing about it is I managed to self-diagnose myself with vestibular migraines ( Mainly down to my symptoms as a teen. I would often struggle to read in school because at times the pages and words would ‘flash’ and I couldn't focus ( Migraine with aura ). I also had travel sickness like my mum and often had to sit next to the car door and open the window to help with the nause on long car journeys. Then we have genetics too. ( My mum also suffered with episodes of chronic dizziness for over 30 years but her migraines were mostly silent )

I then later found out that other half siblings also were on preventatives for migraines years after this illness took its grip on me. So google was GREAT for this purpose. The BAD thing, on the other hand, is it opens you up to so many different and terrifying possibilities as to what you MAY have. A brain Tumour or multiple sclerosis - it runs in the family. But when you have so many scary symptoms, you seek answers out of desperation, and it’s usually in the wrong places!

Even worse, I’m aware that I can no longer work in the office full time. Since my attacks happened I took two weeks off sick and as I am still so dizzy, they have allowed me to work from home on shifts of 4 hours a day. It sounds manageable right? Wrong! Looking at spreadsheets and emails in a dizzy haze makes me feel sick and completely exhausted. Just scrolling is enough to send my head into a spin again.

After one hour on the computer I need to sleep. Then I wake up in my dizzy hell again, stagger down the stairs and do another hour of hell. I HAVE too! I need to pay rent, survive. I cannot survive on statutory sick pay, end of.

This was hard to take in the early stages of my illness. I realised that I should have started saving years ago but I always seemed to just about make ends meet. I had started to save more seriously in the last 18 months but rent would eat into this in just 2 - 3 months! I also didn’t have any family to back me up.

My mum is 66 and retired. She has no savings. I have no family home to go to like I know a few friends have done after traveling or wanting to save up to buy a house. I have no family in London apart from an Aunt and Uncle that I only see sporadically through intermittent years at weddings etc or special family occasions ( Now we are closer ) but I feel I have no one I can turn to when it comes to financial support, I feel very alone.

Even my friends have not really checked in. They just think it’s a virus and I need to rest up. They have no idea. If they could only see through my eyes how things jump and lurch, and feel the dizziness, the off balance sensation, the dropping through the floor, maybe they would understand.

But this is an INVISIBLE illness, and I look fine.

My partner checks in all the time after work and brings me food as I can’t leave the house. He is my rock, but even for him it’s hard to understand. He is not seeing things through my eyes, but he is there for me.

**I am beyond grateful for him.**

The only way to describe my condition to loved ones is ‘Imagine that feeling when you have too much to drink and everything is moving, almost spinning and you feel really nauseous? It’s impossible to walk straight and keep your balance. Now imagine feeling like that everyday 24/7…... for weeks.’

I decide then and there after only two months, that if this carries on any longer than a few more weeks I would rather die than have to wake up to this spinning sensation and dizziness every day. Little did I know then that it would be another 2 years until the dizziness finally started to reside fully.

This in itself was a blessing. As this condition was still not correctly diagnosed and I was still trying to understand it, I kept thinking ‘just another few weeks, it will reside’. If anyone had told me then I could expect a two year wait, I would have checked out.

It’s SO important to talk to people about your feelings in the early days! Most have no idea how hard we are actually finding it as it’s not like we have a broken arm or something to SHOW them we are sick. In fact, the best thing I DID was reach out to my partner later on and tell him how I was feeling and it was too much and I didn’t want to go on as only then, I managed to get the right support.

Luckily for now, I still have hope. It HAS to get better. My inner ear will heal. The Labyrinthitus will heal. In the meantime, I have to fight it.

I go through these erratic periods full of the most extreme anxiety imaginable to long periods of insomnia, to the calm moments of …. ‘I can do this’. My emotions are like a rollercoaster, with some days thinking I WILL get through it whilst other days are filled with complete despair and very very low, dark thoughts.

I used to fall asleep and have the line in my head ‘Tomorrow is another day’ from my heroine Scarlet O’Hara, and then wake up to the room moving and spinning and once again go back to levels of despair.

My days are filled with crying, headaches, and exhaustion so extreme that I need to crawl on my hands and knees to get up the stairs and to my bedroom. When I try to stand my legs feel like jelly and I am so off balance I need to crawl instead.

My days are endless. I lay in bed throughout the day - I have at least 4 dizzy naps a day before a restless, dizzy nights sleep grabbing a few hours here and there - and I cannot put into words how it feels to feel so completely exhausted, it is impossible to life your fingers, let alone your arm.

I lay there, too dizzy to close my eyes feeling the bed rock beneath me. I can’t lift my head, it’s just too heavy but I need to go to the bathroom. I lay there in silence, emotionally numb. The only noise I can hear is the ringing in my ear. Ok, I have held out as long as I can, I HAVE to go to the bathroom now. It takes EVERYTHING I have to lean upright, lift up my legs and force them to swing over the side of the bed and walk the 10 meters to the bathroom.

I sway to the toilet, nearly miss it as I try to sit down, and then I start crying, heaving, no air, no breath, I have to stop…… the headaches will come back, the swollen eyes. I start crying again with a force I did not know was possible.

Then I lean against the wall using my shoulder for support and head back to my room, crash on my bed fully clothed and close my eyes, completely spent in a dizzy, rotating darkness.

It HAS to get better no???

**Tomorrow is another day.**

**September 2015**

I wake up to the ringing in my right ear……. I’m almost used to it by now. As I open my eyes and stare at the ceiling, I feel like the bed is rocking beneath me and again everything moves and I cannot focus on anything for more than a millisecond.

To try and explain this to people, it’s like I can never focus on anything for a set amount of time, not even a split second. Wherever I look things move, almost like they vibrate. It’s also IMPOSSIBLE to know where objects are in relation to you. My spatial awareness is WAY off. I walk into walls and slam into door frames on a regular basis. I’m covered in bruises around my hips which seem to take the brunt of it. It’s like being at sea and on a boat in a big storm and when you look at the horizon, it will not stay horizontal, it sways back and forth.

I’m not going to cry today though. I can’t deal with the headaches or swollen eyes. I am going to say **f#ck you!** and carry on and try to have a normal day as much as possible. I will push myself and walk as much as I can.

From my extensive research on vestibular conditions, I already know you need to stay active and keep going! The more active you are, the faster your recovery! I’m like a toddler learning to walk all over again. The more I avoid upsetting my vestibular system as I have a fear of the vertigo and dizziness, the more likely it will hinder my healing process.

**I am going to get my life back!**

I dress slowly. God damn leggings, comfortable but it takes so much energy to pull them on that I need to lay down on my bed for a few minutes afterwards. Crap, I need to wash my hair, but I don’t have the strength to dry it as the hairdryer feels like a lead weight. Sod it, greasy hair here I come. I pull it back away from my face.

I put on makeup. What a joke, but throughout this, I nearly ALWAYS wore make up! I think partly out of pride but mainly because I wanted to LOOK well! I did not want people to tell me how sick I looked and ‘Are you ok? you look tired?’

My reasoning for this was, have you ever been at work or going about your day and you feel FINE and then a friend or someone says, ‘are you ok? You look a bit peaky / pale / tired?’

Usually, straight away you assume you are coming down with something and actually start to feel WORSE! So comments like this did NOT help me! I knew I was really sick, I did NOT need people telling me it everyday. It just accentuated the fact that I was f#cked. I already looked as exhausted as I felt!

The mind is an incredible thing, you can literally MAKE yourself feel sick just from a comment, or in my case, MAKE yourself feel better by at least TRYING to look ok when you looked in the mirror. As time went on, I started to grow obsessed with if I looked tired that day or not. My dark under eye circles would tell me if I could expect a rough day or if I had a little more energy.

I stagger down the stairs, shoulder pressed against the wall for support, one slow step at a time, swaying. I sway into the kitchen to make tea……. Too much effort. I have to lift the kettle, fill it with water, it will be too heavy, take too much effort, SAVE the energy! I angrily slam it back down.

I grab my trusty cereal bar and sway to the front door and open it wide. The weak midday day sun blinding my overly sensitive eyes. I squint in frustration, but determined, I glance across in the direction of the corner shop. I’m going to walk over there, maybe 100 meters, and buy a chocolate bar and watch films in bed all day. THAT is my mission.

Thank god I already have food being delivered from Sainsburys to keep me going so no supermarkets yet, that torture will come later.

I step out the door into the Autumnal sunshine, the air is cool and crisp on my face. I stand there for a second, everything is moving, the ringing is louder, I have to hold onto the wall for support. I take a moment to stabilize myself and then I am off!

Oh wait, there’s the road. It was SUCH a small road! More like a lane lol. But crossing roads to this day is tricky! I have to check back and forth each direction a million times, much to the amusement of my friends.

Also, I have NO idea how close or far away that car is as I have no spatial awareness and back then I was at least a couple of feet out…… that’s enough to break an arm or leg if you get it wrong, trust me. I’ve had more than a few near misses over the last 5 years.

The street is empty. I step out onto the road making myself even dizzer by looking left and right a million times!

I’m pleased no one is around to witness this. I look drunk. I slowly start to cross the road. I feel like I’m in a dream, everything has a surreal quality, everything seems to be floating and now and again the pavement drops from beneath my feet and I stop and crouch down like I’m about to fall, the closer to the pavement I am the better! I’m 5ft 10 and it always seemed like a long way down when I had this!!

I make it across the smallest road in the history of man. It’s going ok! What an achievement! I lean against the wall leading to the corner shop and literally shoulder it for support most of the way there. It was a particularly bad day to be doing this, my symptoms were at an all time high but there’s no stopping me now!

I make it to the shop and sway through the doorway, shouldering the doorframe hard which startles the man behind the counter. He gives me an odd look but I say ‘Hi’ as normal as possible and smile. He smiles back, tentatively.

WHY does my corner shop have such narrow aisles? Anyone noticed that? You only notice things like that when you need to walk DOWN them!

I take a step forward, lurching into boxes of crisps and grab the shelf like a mad woman, it rocks and things start to shake. The man is still looking at me.

‘I’m just getting over the flu, I’m a bit dizzy’ I tell him. Why did I say that??

Over the next few years I astonish myself with how often I make excuses for my condition. How often I smile in pictures when I go out and share them on social media. - I was a freelance Instagram manager and had to have a good social following to be hired and if you look back at some of my early pics you would not have a CLUE how sick I was as I looked FINE!

My Youtube videos back then told a different story though.

To this day the thing I regret the most is acting ‘normal’. That I was getting ‘better’ as that’s what people wanted to see. I am a very social, active, hyper person always on the go and the life of the party you could say.

Many could not accept the new me so I would try to hide it as much as I could from people. To EASE their burden, but what about mine??

To be fair, if I started documenting my TRUE battle on Instagram back then, NO one would have hired me…… NO WAY! And above all things, rent comes first. End of.

I scan the shelves and see the Mcvities Dark Chocolate digestives! BOOM!

I launch myself at them that only an American footballer in the pro leagues would understand, and feel my way over to the counter, clumsily banging into it ( That damn hip again ) holding onto the counter for all its worth, swaying like a crazy person, and avoiding the man's stare, I pay and then I stumble out the door.

Back I go, leaning against the wall with my shoulder the whole way, rocking and swaying, a cold sweat working it’s way up my back from the exertion of it all. But who cares? I have a whole pack of Mcvities Dark chocolate biscuits and I intend to demolish them within an hour. I sway across the road ( Tiniest lane in the UK ) - still quite thank god - and sway back to my house and make it in the door.

I DID it! I DID IT!!!!

And THAT my friends, is when the exhaustion hits me like a wave. The dizziness kicks in ten fold, the ringing gets louder and I just know I need to get back to bed and lay down ASAP. I clamber up the stairs on my hands and knees. I have just about enough energy to kick off my shoes and then I fall down onto my bed ( Rocking, what else is new? ) and fall into a deep sleep still clutching onto my Mcvities biscuits.

Note: I know that people find it so hard to understand this condition because it changes in severity from day to day. How you were only yesterday able to meet them for a coffee, yet TODAY, you barely have the strength to speak to them on the phone, let alone get dressed.

**Another Week**

I wake up to the ringing in my ear, the bed moves beneath me, I open my eyes to the ceiling. It’s still moving. I have a banging headache, one of many I have had since this all started. I’m in groundhog day…… forever.

The hardest thing to deal with is the anxiety and insomnia. My body is wrecked, exhausted, burnt out, weak, and sleep is EVERYTHING to me right now but I cannot sleep. I toss and turn, everytime I lay back the bed moves and I feel I am on a boat and I will be sick and the drop offs are terrifying, just to all of a sudden feel nothing beneath you like you are falling and then my whole body jumps in panic.

**I NEED SLEEP!**

I can’t turn my head and shaking it is a BIG no no. It’s like the weight of a cannonball is at the back of my skull smashing into it if I turn too quickly.

But on the plus side, I have decided to start going out every day for mini 10 minute walks. I want to get back to normal ASAP and only keeping active and testing my vestibular system will do that.

I stumble/shoulder down the stairs in a brain fog.

I’ve also started to notice when I’m tired I have a new symptom, one of many that will pop up over the next few years. This new one is not the best either. I cannot for the LIFE of me string sentences together. I know the term is called Aphasia.

I get people's words mixed up and even slur like I’m drunk. I will have this on and off for the next few years whilst I battle this condition and try to get back to a sense of normalcy. Or the NEW normal as I like to call it.

( Brain fog will continue to haunt me over the next few years. God knows how I managed to even write this book, a feat in itself! )

At the time I had 2 flat mates, 1 live in landlord that worked from home. ( I would avoid him as much as possible because I did not want him to know how sick I really was and that I would have to ask the council for support in paying me rent, one thing he wanted to avoid at all costs. ) The other called John that worked full time and I hardly saw him but he was lovely.

I pull on the easiest clothes I can manage, leggings and a T-shirt - My daily uniform to this day - grab a cereal bar and start with laps in the garden.

The garden is about 11 ft by 10 ft and tiny lol, but everyday I go out and touch the wall and then come back and do laps. I am trying to build up my daily tolerance as I am so dizzy and my balance is so shocking, I need to start small. After about a week of my mini garden laps ( God knows what the neighbors thought ) I decide to head out and walk down my street.

Again, I hold onto walls where I could and stay well away from the roads. I kept this up for a few weeks until I could walk a lap around…… the block. It doesn’t sound like much progress but believe me it was! After each mini journey I would head home and take a few hours to rest and recover from the exertion. Then start again all over the next day.

( I was dizzy 24/7 for at least 2 years. I feel PPPD has a lot to account for this, but over these two years there was a definite change in the severity of the dizziness which is important to note! For example, on a bad dizzy day I am bedridden or housebound. On a milder dizzy day, I can go food shopping, take longer walks, cook dinner, and function a lot better but I will STILL feel ‘off’ in my balance and also my vision and objects will move unnaturally but it is much less noticeable.)

My vestibular system is probably equivalent to a 2 year olds right now. It was broken. It has to be taught how to do the simplest things again and only time would heal it. So my dizzy laps would continue, the garden, to the end of the road, to a lap round the block, and then venturing on to the BIG stuff! Hammersmith high street.

**Hammersmith High Street**

I practically live in central London. This is both a blessing and a curse.

A blessing as I HAD to adjust very quickly to my chaotic surroundings, and I SWEAR this got me better faster.

I was tested EVERYDAY living here. I cannot handle loud noises, bright lights, too much movement and it was all going on here in abundance!

I liked to see myself back then as a mini Rasputin. Legend has it he took small amounts of poison everyday until he was practically immune to their effects ( Thanks History Channel ). This is what I am doing now. Taking little bits of poison everyday until hopefully, I will adjust and build some type of immunity to my manic surroundings.

So here we go! I walk from my quiet street in Carthew road, Brackenbury Village into the bustling high street. There are SOOOOOOO many people! I stand and sway for a second trying to take it all in but it seems that my eyes cannot catch up with me when I turn my head. Vestibular overload! I come to my senses and I jerk forward. The pavement seems so small and I start to get angry with people practically walking into me…..until I realise they are actually at least a foot away.

Once again my spatial awareness is way off! Wow so many cars, I wince as a loud motorbike whizzes past. Why do they HAVE to do that? Rev up in the highstreet RIGHT next to you? I want to slap him off his bike. The noise still reverberates in my ear drums and makes me feel even dizzier. The anger starts to rise up in me again, that I have to contend with this every day and live in a place like this. I know I look drunk. I get some odd looks as I sway very slowly up the high street, zoned out completely, in a surreal dream, completely numb.

I feel the cold sweat creep up my back again. It’s all too much. I have to go home. I cross the main high street road. Nearly impossible! I think the cars are going to hit me, they seem so close, I cannot take in all the traffic, it’s too much!!

I manage to stumble onto a quiet street again and shakily head home. The experience has left me so exhausted and at the same time wired, I am shaking and my legs are like jelly.

Ahhhhhhh Jelly legs……… the amount of times you kept me bedridden for days on end.

I swear my legs are about to give way, they are tingling and I can’t really feel them. Here I am! I am back at my door! I fling it open, drop to my knees and crawl up the stairs into my bed. It takes all the strength I can muster to remove my shoes. It takes a few minutes in fact. I have nothing left in me. I am spent.

I lay back and pass out, ears ringing, head spinning and a strong, painful throbbing sensation in the back of my head.

The headaches are back.

**December - The battle continues**

Things have gone down hill at a rapid rate. I can no longer wake up and turn on my laptop and stare at spreadsheets, even for 4 hours a day with breaks.

My job is currently letting me work from home part time but I am about to tell them I need to stop and go on long term sick leave. This was NOT an easy decision to make. Trust me, if I had the savings I would have left over a month ago and just had complete rest.

I am still walking every day, dizzy 24/7 and still pushing myself daily. To be expected to work at the same time whilst fighting the hardest illness I have ever come across is impossible.

I need a miracle.

I am out of savings, I cannot pay rent, I am basically screwed. I know I need to leave my job and the realisation is hitting me that this could go on for months, dizzy 24/7.

I need EVERY ounce of energy I have for my recovery. My partner is always coming over to see me and I stay around his too and he really looks after me, but at the end of the day, I still need to support myself financially.

The stress is IMMENSE! I didn't realise it at the time but stress is to this day my BIGGEST trigger! I don’t yet realise that worrying constantly about losing my room, job etc and how will I survive is actually making my condition WORSE!

But I CANNOT stop with these ruminating thoughts! I have always been a super sensitive child, prone to anxiety and over thinking and with this on top everything has just snowballed.

I am a nervous wreck yet I STILL go out everyday for my wobbly walks.

This illness is also on and off. One moment I feel like I am recovering and I am proud that I walked for 15 minutes straight before the dizziness kicked in, the next I am bedridden, too weak to even crawl downstairs and make tea, let alone get a glass of water.

What am I going to do? My mum is coming up to 70, she does not have any spare cash lying around, she helps me out whenever she can and I feel so guilty!

Every day is the same routine.

Wake up, ringing in the ear, open eyes, the ceiling is moving, everything is moving! Stand up, sway, clamber down the stairs holding on to the wall for dear life, cereal bar, leave the house, a dizzy 10 minute walk.

Cold sweat, exhaustion, jelly legs, I think I will fall, I feel like crying but I don’t at all costs, avoid the headaches and swollen eyes! Walk home, crawl to bed, sleep.

Something HAS to give, surely this cannot go on forever??

The hardest part? Friends and family do not fully understand, I sound fine on the phone, I look fine, just SUPER tired. Thank god I have my mum! She has suffered from similar symptoms for 30 years! She understands the swaying, dizziness, anxiety.

It brings us closer together. If there is anything good that came out of this, it is the relationship with my mum. She is the ONLY one that truly understands this.

It’s nearly Christmas, I am meant to be going round my partners in Essex with his family.

The first trip ended up being incredibly embarrassing. I was in the peak of my dizziness when I met them for the first time. His mum, a lovely woman, is a bit of a talker and I just cannot take in what she is saying.

I find when people to this day, talk to me for any length of time I start to ‘zone out’. I no longer can take in what they are saying and if I am standing up I start to sway, I feel exhausted, dizzy, I have to lay down.

It ended up that I got so sick with excruciating headaches and dizziness I had to stay with his family in their home for 3 days whilst my partner went back to London without me - he works in central. He would come home to his parents every evening to check on me and stay over until I was well enough to travel back. Can you IMAGINE how embarrassing that was? The first time I met them?Great start no?

On the plus I had COMPLETE rest for 3 days and just sat in my room and came down for dinner or cups of tea and felt truly cared for to the point my gratitude for them brought me to tears at times when I was alone in my room.

Christmas is next on the list, and I am honestly dreading a big get together round his with so many people, noise, children, all the things I usually love in life!

I’ve become a different person, someone that wants to become a recluse and avoid anything that can make me feel exhausted or dizzy. I’m a shell of who I used to be and I still see no way out of this hell.

**Christmas 2015 - Home Alone**

It happened, I cancelled Chritstmas.

I was meant to be spending it with my partner at his family's house.

A few days before, my symptoms started to worsen until I was mainly bedridden apart from getting up to make the odd cup of trusty tea. Us Brits eh?

The dizziness increased and I knew I would never make the journey on the underground, then to bustling Liverpool street and then another train to essex.

It’s not just the train, that’s only half of it. It’s the talking. I CANNOT talk and it’s even harder to listen. If someone talks to me for more than 10 minutes straight I lose focus, I get brain fog and start to sway. I need to hold onto the kitchen counter to stop myself from falling and then the nausea kicks in.

I can’t be rude, I am so embarrassed too. I try to hide my condition but I just can’t! Christmas with at least 10 people in the house, children and noise is a no go.

Once my partner makes the announcement that I am too sick to travel, I feel a MASSIVE sense of relief. I will be home alone, watching films and it will be peaceful, pure bliss! I will not need to act or pretend I’m OK, smile and try not to sway.

My partner leaves on Christmas eve and I will spend 2-3 days alone. I buy Baileys and treat myself to my favourite foods knowing the shops will close over this time and I need to get enough in incase I become bedridden again.

For those that ask, Alcohol for me has always taken the edge off and I have never had an issue drinking it. In the years that pass I learnt that alcohol is a vestibular suppressant and that’s why you can feel like it takes the edge of your anxiety and then the dizziness. If a weekly glass of wine or two helps ease the anxiety then do what feels right for you. Just be careful you do not become reliant on it. We are adults, it is up to us to work out if we feel we can drink it or not or that’s it’s a trigger. P.S Wine is a massive no go for me!

**Christmas Day 2015**

I wake up alone in my partner's flat and the first thing I hear is the ringing in my ear, followed by the room moving and then I notice the exhaustion. I can barely lift my arm. The usual then.

( I didn't realise it at the time but the build up of stress & anxiety of not being able to take part in Christmas with my partners family have flared up my daily symptoms even more. )

I go to the kitchen, grab anything I do not need to cook and then crash on the sofa. I also grab a duvet and pass out for the whole afternoon, quite happy that I can just rest completely.

I make the usual calls to family and friends and I seem to be OK being on my own on a day that’s usually spent with loved ones.

It’s only when the day turns to dusk and the sky grows darker that I see all the Christmas lights shining in other peoples windows, that the depression kicks in.

I am home alone for Christmas, completely alone.

All of a sudden the realisation of my situation kicks in and I start to cry….. and I don’t stop. Literally for an hour I cry and cry and cry until my eyes are so swollen it’s hard to see out of them and my head is throbbing with the worst migraine possible.

I am completely alone. I have no life. No one understands what I’m going through. No one understands how hard it is to ‘act’ normal. People will usually give you some respite at first, but as they get used to seeing you everyday with this condition, and they do not get a positive response to ‘so, are you feeling better?’ they stop asking and their patience with you wears thin. You are no longer the person you were before and to them, it’s easier to avoid seeing you or checking in with you.

So I act.

( Over the years I become an expert at it…… until there comes a time where I simply say ‘fuck them’ and I give up caring WHAT they think. After 5 years, I’m acted out.)

It’s a frosty night and the sky is clear and as the stars start to appear, I decide then, ( not for the first time…. ) that if this carries on I refuse to live like this anymore. I start to spiral. I start drinking Baileys, one glass, then up to 6 glasses. Anything to numb myself and relieve myself from this headache. Anything to help me pass out and get a good night's sleep. Anything to make me forget……...

I know I am broken and there is no cure.

I am alone.

**January 2016**

It’s official. I have handed in my notice to my work. After being signed off for a month I knew I could not return and work to the computers again.

I am still dizzy 24/7 with speech and visual issues not forgetting the insomnia, anxiety and exhaustion. Something has to give and it looks like it will be my job.

My dream job was to go into the content writer field in the travel industry and I really thought my career was finally heading in the right direction. I had already started to think about leaving after the 1 year mark and going onto the next stage of my career.

Now it was all over.

Shit just got real.

It doesn’t truly hit me yet as if anything, I am more relieved I don’t need to put on a facade that I can manage, but later on, the fact that my life is dropping away around me causes serious depression.

I cannot even begin to explain the fear and daily anxiety I have felt over money the last few months and how I will support myself. Now I can no longer pay rent and the landlord does not want any people on benefits. He’s very strict on that, even out it on the ad.

I have decided to look into other ways to support myself. I cannot work at all so JSA is currently out of the question. Now it’s time to apply for ESA and apply to the government to cover my rent, at least for a short period of time.

ESA stands for employment and support allowances so if you have been suffering from a long term illness for example, you can expect around £70 a week. Barely enough to feed and clothe yourself, especially with medication prescriptions to pay for too but better than nothing.

I have my ESA interview booked near Parsons Green. I have already filled out the ridiculous questionnaire which asks things like….

**Can you wash your hair?** - Er, yes, it’s been over 7 months now and I can just about manage that task, but that does not mean I can stand on my feet all day or look at a computer screen and I need to go to bed and rest afterwards for at least 2 hours as I am exhausted. By the way, if you CAN wash your hair, that counts against you on their point system.

So it’s the day of my interview and I am so apprehensive as I LOOK fine. I nervously wait until I am called into a treatment room where a lovely lady is there to assist me. You can see the look of pity she has on her face as we start to go through the routine tests as she knows already I will not be accepted. I am basically screwed.

She asks me to lift my arm above my head……. I do.

She brings out a set of 3 steps and asks me to climb up one step……. I do, albeit wobbly.

Now, because I can lift my arm above my head and stand up on ONE step, this qualifies me to be able to do SOME form of work.

This to date has to be the biggest joke EVER! I see people screwing this system every day and claiming benefits and there is me, dizzy 25/7 surely a hazard to myself and others in the workplace and because I can lift my hand above my head and climb ONE step, it counts against me in the points system that they have and I am later informed I cannot claim for ESA as I am basically NOT sick enough.

NOT SICK ENOUGH!

So whoever wrote these terms, congratulations on being a MASSIVE wanker and letting so many people that genuinely needed the support in dire circumstances down.

Just because people with vestibular disorders can lift an arm above their head or make a cup of tea unaided, does NOT account for how they can manage to stand up 8 hours a day in a job with bright lights, loud noises, movement whilst suffering from severe brain fog, vertigo, balance issues, anxiety and chronic fatigue.

The same goes for a desk job with computers! And if you can find me a job, it would have to be 3 hours a day as I need to sleep the rest of the time to recover - please can I request one with NO bright lights, NO loud noises, NO visual disturbances, NO excessive talking, NOTHING that requires a lot of thinking or brain power and one that is very calming and COMPLETELY stress free.

Yep, you get the idea.

I felt SO strongly about this that for a while I tried to start up a petition to change the rules or at least for them to be looked into further but there were not enough VM sufferers to take our case to parliament at the time.

I could have appealed, but it is a long and lengthy process, one that at the time I did not have the energy to fight when I found out that a lot of VM sufferers were turned down a second time too.

I basically felt let down by the government, the one I had been paying taxes to for the last 20 years.

But PLEASE, this was nearly 6 years ago now, so if you apply for ESA today and fail, PLEASE follow it up and appeal with everything you have!

So now I need to sign up to JSA which is the most ridiculous situation ever as this means I need to apply for over 50 jobs a week which I know for a fact I cannot actually do! I think you need to spend something ridiculous like 25 hours a week. Like THAT’S going to happen on my laptop!!!

I feel completely let down by our system, especially as I have always worked really hard in my career. Even when I started college at 15 I would then work after my studies 6- 10PM night shifts Monday - Friday to support myself. I was completely crestfallen. I just felt like every available avenue for financial support was blocked.

**March 2016**

A small miracle has happened, I managed to claim money to cover the rent of my room! The issue is the landlord is not happy about it and it has become very uncomfortable at home. The landlord is live in and now I am live in too and I'm still very very sick. The tension starts to mount and although we get on, I realise he will not accept this forever and I am on borrowed time.

I am meant to move in with my partner into his new flat near the end of the year, but things have come to a head and I have to move in sooner, much sooner that what he was really ready for.

It puts an incredible strain on us as a couple and as the years go by he is turning more into a carer than a boyfriend and I can also see over time his mental health declining too.

He lets me off rent nearly all the time and when I do pay it is very minimal. But I still need money to support myself as in food, clothes etc so the battle continues to find money.

I will say this, there are therapists JUST for carers and I think it’s just as important to support the person looking after you, especially if they had not expected this. An illness like mine was constant in the first 2 years of our relationship and although we still had a lot of love for each other, my anxiety, depression, chronic illness combined with his 10 hour days working in finance came to a head. It was just too much for us to survive it.

He would go to work at 6 A.M and then get home shattered at 8 P.M to a very sick, depressed girlfriend. At my very worst,there were times where he had to leave food by my bed in the morning as I was just too sick to make it to the kitchen, I could barely manage the bathroom other than crawling on all fours.

He also helped me to learn to walk again through this tough period. Due to a complete overload of my vestibular system and the stress, I started to get jelly legs so badly that I could not stand, sometimes for weeks this went on!

So he would come home after a long shift and then have to hold me up, literally whilst I walked the 500 meters around our apartment block to ‘get some fresh air’ and it took EVERYTHING I had to take those steps and not fall down from complete exhaustion. Every day…… for weeks. How are you meant to find times of joy, intimacy and romance when you have this??

Also, the pressure on your relationship gets harder as you try to put on a happy face to show you are not a burden and you are ok and can take care of yourself, that you are strong etc, and that’s where it comes crashing down.

The resentment starts to creep on a little for both of you. You because you feel you cannot just ‘be’ and have to act that everything is OK all the time when really all you want to do is cry and never get out of bed again, them as they have to deal with this day in and day out and they get tired of the constant stress and having to deal with someone who’s moods can rollercoaster from one day to the next.

It was not all bad, looking back at our photos of us laughing, travelling, our goofy humour, I can see how much we really genuinely did love each other back then, but the illness ended up outweighing it all.

My biggest hope for all of you not to give up on love because of my story. I know PLENTY in our migraine group who’s partners stuck around over the years. Yes, I know there have been many break ups due to this illness, but I also know many of us found love again so hold in there and do NOT give up on love if that’s what you really want in your life.

It’s important to mention it was just as much of a relief to be on my own for months after my break up too and not have to put on an act for anyone. But that’s up for you to decide.

**The Weekend Break - Brussels**

I am ready to board the Eurostar. I am dizzy and nervous and still off balance. It’s been 8 months now and I have been working so hard to walk every day and build up my tolerance to vestibular stimuli.

The ringing is still there in the morning but less noticeable unless I am having a bad day. I can’t seem to break the 15-20 minute walking barrier yet and as soon as I go over this point the dizziness and exhaustion kicks in and I need to rest or sit down suddenly.

My anxiety starts up and I worry I will get sick on the train. I sit down and breath deeply, my partner next to me and we order a drink. I then focus mainly on my book and avoid the scenery outside whizzing past me.

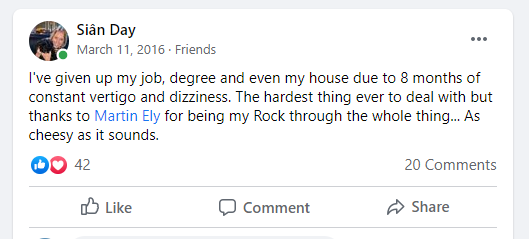
My symptoms are still daily dizziness and not being able to focus clearly. Some days the dizziness may lesson for a few hours, but then it returns and it is NEVER completely gone. As for the exhaustion, it is always there but at a different level each day depending on what I have done.

It’s the hardest thing you will have to deal with on this journey, to get the balance right. TOO much and you can expect to feel drained for the next few days and even cooking dinner or washing your hair will seem impossible.

Then you recover, push yourself again as you think you feel better and it comes back again. The trick is to stop just before you think you have had enough! And that’s easier said than done!

Also, in the early days it took me ages to get over a long walk for example, maybe even a week of being housebound for an hour's walk! As the months and years went on, I adjusted and could do a lot more. I am now rollerblading! I can only last 15 minutes before the exhaustion kicks in but again, it’s all a process and in a few months time I would have built up my stamina again and I hopefully will be able to skate for longer.

In the words of our lovely admin Chloe, ‘THIS IS A MARATHON NOT A SPRINT!’

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**March 22nd - Brussels Bombings**

I first woke to the sound of fire engines…… and then more fire engines. When I started to hear the police cars too and the fire engines continued for another solid 10 minutes, more and more being called from around the city, I knew this was more than a fire.

Living in London, you become highly aware of the possibilities of a Terrorist attack and the signs to watch out for.

There’s been a bombing…… I thought.

My partner woke up and checked his phone. He was inundated with calls and Facebook messages even from my brother that had never met him asking if we were ok and there had been a terrorist attack on the underground up the street from us.

I checked my phone too and had so many missed calls from friends and worried family members. We called them straight away and then I turned on the T.V.

We could see the chaos before us and learnt there had also been an attack on the local airport.

At that moment, we heard a knock on the door. It was the hotel manager. He was knocking on each door to tell us not to worry and we had 2 armed policemen on their way to secure the front. Yes, it hit home at that moment.

Were we a target?

As the day went on, being glued to the TV news channels was both a blessing and a curse. We found out that the bombers came from the neighbourhood across the street from our hotel and we were staying in a place called ‘International square’ where all the international hotels were and we were, according to surfacing reports ‘next on the list’ and a target.

It honestly was terrifying.

It’s the not knowing. The police said they were still looking for more bombers and they had other targets around the city too. You need to remember at this time a lot of people were calling in to report suspicious people so any threat was taken seriously. We didn’t know what was real and what was not. You hear of specific locations that apparently are being targeted or that have had emergency calls and police surrounding the buildings and all you can think of is, are they close to us?

Fear does funny things to you, and in my case with vestibular migraines, I actually went into focus mode. I do not remember the dizziness at all.

I told my partner to stay away from the window and we worked out where the reception was and wondered if it would affect us if something went off there. Then I started talking about hiding in the cupboard if anyone comes in or taking a mattress to protect us if there is a blast outside by our window.

My partner was very calm during this time and just watched the TV and news reports tensely. I knew he was fearful but he hid it very well.

During this time, I just wanted to get OUT of the hotel, I felt like a sitting duck just waiting for something to happen. We left the hotel to get food. I told him I would rather be in an open space near a quiet park where we can hide or at least run than be trapped in a building that is apparently a target.

After a few hours, he said it'll be OK and let’s go back to the hotel.

We were pretty shocked to see that the army had been deployed to our hotel. Armed troops surrounded the front of the hotel and reception and army trucks filled the square. I remember being so grateful that they were there, to look after us and at the same time even more nervous as I thought we must really be under threat for them to send out the army!

The whole time from what I can remember, I was living on adrenaline and did not notice any dizziness really as I was so wired and scared. Living in London, after an attack you always feel on edge no matter where you are in the city, or anytime you use the underground. You really can sense fear in the air and all I thought was ‘it’s followed us here’.

We felt a lot safer with the armed guards outside and as the day crept on we started to hear about the death toll.

Altogether over 300 people were injured in the attacks and 32 lost their lives. All my thoughts go to their families and friends, it was absolutely devastating. You go through a mixture of feelings, a deep sadness for the growing death toll and the loss of lives and also the fear that it is not over, and to be hyper vigilant.

We were leaving the next day. I remember the dizziness kicking in on the way home once the adrenaline started to leave my system and the numbness left. It took a while to get over it as my body was on such high alert for such a prolonged period of time that the exhaustion and balance issues kicked back in with a vengeance.

I also felt very on edge coming off the Eurostar and walking into St Pancras station as there were armed guards everywhere and police dogs and I just thought it could be London again next.

I want to say a massive thank you to all our emergency services and the forces that continue to put us all first to try and keep us safe, in ALL countries.

I had really put my VM to the test that day and I realised if worse comes to worst, you really CAN push through if you have too, the mind is an incredible thing.

I also realised there were roughly two trains of thought in the migraine groups. Some just had given up ever getting better or recovering and they would stay in the house all day to avoid any movement that would make them feel dizzy meaning they were trapped as the only way the vestibular system will heal is if you keep it active and get it used to doing activities that will make us feel uncomfortable at first.

There were also people that had given up on advice or information about meds and techniques that may help - I get it, I have been there too a FEW times where I just thought I want out and I was sooooooo tired of living this way and trying that I would cry it out in the bath, but then i found this release helped and I would try again the next day. I also went to see a therapist when my moods became particularly dark.

But what I REALLY noticed is the ones that recovered were all pretty similar in their positive outlooks and can do attitude.

They lived a full life to the best of their abilities, they went on holiday, flew on planes, went back to work and at my lowest they would tell me it’s a marathon NOT a sprint, and just rest when you need to and push when you should and literally, using this method I would say I have got back to around 95%.

Yes, I still have relapses when I over do it and I am under extreme stress and I am aware that it can come back at anytime, trust me, the fear is what I am dealing with now and it’s a little like PTSD, but overall, I think I have my dad to thank for that as he was ex special forces in the marines and he taught me the mindset to get up and to keep trying.

So if you are reading this now, even if you just walked outside today a few meters and made it back to your house after not leaving for weeks, that is a MASSIVE MASSIVE achievement.

The mind TRULY is incredible!

I remember reading about the 1972 Andes plane crash carrying a team of rugby players to Chile that crashed high up in the mountains. They were starving and they realised the only way to get out was to climb out.

They hiked over 80 miles in 10 days reaching peaks of over 15,000 feet and they made it to safety. This was actually considered PHYSICALLY impossible as the mountain goats that lived in the area had only been known to reach heights of 13,000 feet, in their NATURAL habitat and these men were fish out for water.

The ONLY reason they survived was because they did not give up hope and they KEPT on going. Again, it's all about mindset. And what if like me, you do not have that mindset? You are NOT a positive person naturally and are a constant worrier? Then it literally is one step at a time. Just getting up and walking those few steps, a day at a time.

**April 2016 - Is it REALLY labyrinthitis?**

10 months in and it looks like I am finally about to get some answers…… or should I say I found my OWN answers. I was the queen of Google search. This both terrified me and gave me clarity.

I came across a condition called vestibular migraines after I was searching for what could cause dizziness for soooooooo long.

So far, it all made sense, but at this time, my migraines were not that frequent and I assumed it could not be that until I looked into the condition further.

The bright lights, too much movement, loss of balance, feeling like the ground is walking, loud noises all seemed to add up and I then remembered my teen years. I was an avid reader and would literally read for hours until the words would start to flash and I was unable to read anymore.

At the time I thought it was just eye strain, I now know this was actually a migraine with aura. I also remember being sick regularly every month when my periods hit, the exhaustion I felt I just could not explain.

I just always FELT there was something wrong with me you know? How could a very fit and healthy teen that played football and hockey for the school and ran for the county be so exhausted ALL the time?

It just got worse as I went into my 20’s and I started to take more time off work. I always had a cold, sinus issues or I was just so run down I could not function and I also could not push through either, if I did it made me worse.

ANOTHER massive clue I missed all these years, I was ALWAYS thirsty and I used to get headaches and drink as much water as possible but no matter HOW much I drank, I would still get the headaches.

Again, I know now this was due to migraines. But what REALLY sealed the deal and persuaded my doctor to refer me for CT scans and to see a migraine specialist?

Family history.

My mum has suffered from intense dizziness for nearly 40 years and also could not handle bright lights. When she is anxious, she also gets dizzier. Yep…… She has vestibular migraines too although she is still to get an official diagnosis.

We then have my half sisters, who ALSO suffer from terrible migraines and rely on preventatives.

With my new found knowledge, I went back to the doctor and literally begged to be sent to a specialist. This was after countless trips to see different doctors that tried to fob me off with anxiety, depression or stress as they were confused how the labyrinthus could last THIS long.

There are roughly over 300 conditions that can cause dizziness so I could not completely blame the doctors in a crowded London surgery for giving me the time I really needed, I honestly had no CHOICE but to look into it myself.

The doctor said she would send me to a migraine specialist called Dr Barry Seemungal, a migraine expert. In the meantime I was sent for CT scans to discount anything else………. Exactly.

This is where google does not always come in handy! After some research you can convince yourself the pain in your head could be a brain tumour for example and after getting the CT scan done, the wait for the results is terrifying, especially in a mind that is already on the brink from anxiety, lack of sleep and dizzy 24/7.

Lucily, the results came back clear, there was nothing out of the ordinary that they could see. I was now on my way to see Dr Barry Seemungal. I FINALLY felt like I was getting somewhere!

My appointment was booked in June.

Until then I had to wait and it was a LONG wait!

I had already been put through the mill with countless blood tests - which all came back normal - eye tests - all normal - and hearing tests, all for labyrinthitis which they now thought was vestibular neuritis.

In the end it took over a year to be properly diagnosed.

**April 2016 - The Flight**

We are going to Scotland for a few days and I am flying.

I am petrified.

I have flown easily over 45 times on and off over the years as I lived in other countries so my fear makes no sense. I am scared of feeling dizzy on the plane and my biggest fear is being sick in front of everyone.

I had already been sick once before on my first ever flight to Italy aged 19 and I have been paranoid about it ever since!

In all honesty, the flight was not a good one. We lurched taking off and it was a smaller plane than usual as it was only an internal flight. Because I was so terrified my anxiety was at an all time high and everything was moving, I felt at times when we had some turbulence that I was floating and I seemed unable to control my eyes as we took off and they did their own thing as they tired to work out what was going on and which way up I was!

My back was in a cold sweat and by the time we landed only a few hours later, I was completely spent and emotionally and physically exhausted. I passed out that night and it took me most of the 4 days we were there to recover before I had to fly back again.

After this experience, believe it or not I STILL flew multiple times but my anxiety was now triggered with a fear of flying and the vertigo that came at take off. Days before I had to get a plane I would be tearful, unable to sleep and terrified.

It got to the point where I had to run to the toilet as I thought I was going to be sick before we even GOT on the plane as we queued up to board! I was NOT going to let this stop me, it had developed into a full blown phobia so in the end I actually booked to have a hypnotherapy session in London.

The procedure I thought would not work, and yes, there was a lot of counting involved lol! I had to focus on flying and recognise how it made me feel, the anxiety, the fear, and then I would count down from 40.

After the session which took around an hour, she told me to think of flying and how I felt about it now. Oddly, the emotions that came with the thought of getting on a plane felt blocked somehow.

Yes, they were still there but had gone from a 10 to a more manageable 4.

This was truly a miracle! I had another flight to Tenerife in a few months' time and was able to test it out.

Was I STIlLL anxious? Yes, but no way near how badly I was before, no running to the toilets as we queued to board and no nausea, I still felt some fear of course but the most important thing to take from all this was that now it was MANAGEABLE!

**Here are a few tips when it comes to flying again!**

* Do not sit in the waiting room where you can see the plane before you board! This just increases your anxiety!
* I have tried propranolol and even diazepam to take the edge off too but now I prefer CBD oil or Kalms herbal tablets and it is an afternoon flight, a glass of something strong to take the edge off! ( Obviously don’t mix heavy meds with alcohol! )
* I find a coffee shop or restaurant that reminds me I am NOT in an airport. For example, ALL starbucks or Costa coffees have the same layout. I would sit in one of these and read until the very last minute when I had to board and because it was familiar to me as my local Costa, it lessens the anxiety that I was in an airport and had to fly soon.
* Buy a gossip magazine! You need one of those magazines you look and think, OMG, what have they done to themselves? Yes, they can be trashy but trust me, when you take off, it’s the best time to read it and distract yourself. Unless you want to be blown away by the financial times that is lol.
* Buy ear planes. They help with your ears popping and being painful on take offs and landings. The majority of us have probably suffered from some inner ear disorder alongside this illness and this takes the edge off.
* Take an iPod. Playing calming classical music if it gets bumpy really really helps! Remember, most of these techniques are about DISTRACTING yourself.

This really helped to get me through and also I would definitely advise looking into hypnotherapy if your fear was as bad as mine.

**May 2016 - Finding work**

I know I’m in trouble.

I am now on Job Seekers Allowance after being turned down for ESA which means I am expected to spend around 25-30 hours a week looking for jobs……. whilst I am constantly dizzy, can’t see properly, walk far or stand for too long OR use a computer….. I know.

So I think about the jobs I can do, I can’t do any office work, no computers, I can’t do childcare, I am too dizzy to do even the simplest things myself, it wouldn’t be safe. I can’t do factory work, the repetitive moves, the 8 hours standing, there is no WAY!

I can’t be on the phone in a call centre, I can only talk for around 10 minutes intently before I get really dizzy and my vision starts to blur. I literally have NO hope of finding anything yet I am EXPECTED to go in every 2 weeks to show the 35 hours work I have done finding a job!

Luckily, at least the guy looking after me there really feels for me. He sees me every 2 weeks, looking drained, black under my eyes, wobbling over to him to sit down, holding on to walls as I sway and wait in line and yes, I have teared up a few times.

He tells me that if I can not find a job in a few months time then I will have to have a special interview where they can pick something for me if they deem I am being too fussy or try and help give me the skills they think I am lacking. I already HAVE the skill sets, I just can’t do that particular job anymore!

I started looking for a work from home job, anything! I found a PA company locally based in Wimbledon and applied for a marketing manager role which would only be around 4-5 hours a day 5 days a week……. I love the way I say ONLY.

I am bedridden some days and on others I can't walk at all, but there is no choice, I have no money, no family that has the money to support me. I am completely screwed and the fear is really getting to me.

I do not want to put added strain on my partner. I do not pay any rent as it is - which was not the original plan when we discussed me moving in before I got sick. I have realised that as much as he tried to support me emotionally, I feel resentment towards him sometimes as I feel he does not understand how bad I feel and I’m tired of trying to be upbeat to make his life easier too. I know his is creeping in too.

He is doing all he can for me but he has limits too which I’m sure if you spoke to carers of family members they would tell you too how draining and depressing it can be.

I worry we are starting to resent each other……… ME for not being able to just ‘be’ and feeling like I have to keep it together to make it easier for HIM and HIM for doing such long shifts to come home EVERY day to a partner that is very sick, and having to walk her around the block every night when he would rather be resting. Include all the added health issues that seem to crop up every week.

The guilt and shame I feel is immense. I am completely broken, unfixable.

Something in me always wakes up the next day though and carries on. You don’t know the meaning of the word resilience until you have a chronic illness.

I call the PA company and arrange to have an interview in a cafe in Wimbledon. Before I meet her I have to create a massive media pack with intricate data on social media presence, a whole website review, google analytics reports, you name it to nail the job.

I manage to do this in a day, and sleep on and off, exhausted for the next 4……. I am so dizzy, I have no idea how I can hold this interview together. I cannot talk for long, let alone get a train.

But there is no choice.

I won’t go into details here but I someone how managed to get through the interview mentioning due to migraines I worked from home now. She did ask me if I would be OK to do this type of work and of course I said yes.

I need money. Plain and simple.

Let’s just say the following 5-6 months were incredibly difficult when it came to my job. I had agreed to write 3 blog posts a week on social media tips for small businesses at 500 words a piece and that was only HALF of my job.

Not to mention hours every day doing social media likes, comments etc on my phone, even well into the night.

I was completely, and utterly exhausted. I would wake up, go into the living room - we lived in an apartment complex surrounded by other apartments that blocked out a lot of the daylight - and by 3 in the afternoon in winter the little natural light we had was gone and you would have to turn the lights on - pull out an ironing board - my desk - and start typing.

There was no choice, as simple as that. I will forever be grateful that at least I had a roof over my head, the alternative would be to crash on a friends couch and she had two young boys at the time and I knew that would only work for a week or two.

I was basically screwed. This was a very dark time for me and I am certain my depression really took a turn here.

I’d wake up, ringing in my ears again, dizziness, making my way to my makeshift desk in a dreary living room which was very grey with little light. I would sit there, exhausted, researching and typing up blog posts.

The 4-5 hour days were just too much, I was using energy I did not have and constantly had to be on the go, sending emails to a big team and doing lots of data and analytical work.

Then I would crash on the sofa, wait for my partner to come home, watch T.V and sleep then do it all again. I felt trapped, both in the house and in my condition.

Trying to ‘fake’ you are well to keep your job is so tiring. The only reason I GOT the job is because I kept up a good social media presence in the first place on Instagram - This would come in handy in the future once I started freelancing for myself - but on the down side, I NEVER spoke about how crap I felt, dizzy, that I was losing hope.

I couldn’t, I was playing a part, to show people I WAS getting better. After all, it was nearly a year now, they were getting tired of it. So I put my makeup on and smiled, and posed.

In one way I’m pleased I did, as it kept me in a job when otherwise I would have been screwed - if they knew the truth, no one would hire me - in another way it was NOT good as people thought I was fine.

‘Oh look at Sian and her partner having lunch! She looks better!’

They had NO idea that it took up to 3 days to rest and that I went out for one/two hours max - I could still only walk 20 minutes tops at the time - ate dinner/lunch, came home and passed out. That’s why NOW I want people to know about it!

NO more hiding!!!

Back then, I cried….. A lot. I would think…...so THIS is how my life is going to be? And questioned whether I wanted to live it. All I wanted to do was sleep and not wake up. To not worry about money, being sick, not getting better, my friends and relationships that were growing further apart from me day by day, week by week.

It had been one year of constant, 24/7 dizziness with periods of the most excruciating migraines. I likened them to a heavy cannon ball rolling around in the back of my head and smashing into my skull.

I could still not walk far without feeling exhausted and dizzy. I had had enough. God knows what made me get through that dark time. I am very grateful for my partner though, I honestly do not think I would be here if it were not for him.

Tips - To get me through having to use the computer for long periods in the day, I used computer glasses that had a yellow tinted lense. They really did take the edge off the brightness and glare of the screen and I also used these years later when I worked in schools as a TA to combat the strip lighting!

My glasses were unbranded and cost £9.99 on Amazon!

**June 2016 - Tenerife**

Holidays for anyone that has a vestibular disorder are incredibly stressful.

The anxiety I would have before I flew was crazy, so much so that I had to take anxiety meds just to get to sleep. But the biggest issue was this was a big family holiday. My partner's whole family would be there so that would be at least 12 people meeting regularly in the day and in the evenings for dinners etc.

I was still dizzy 24/7, I rarely had good days at the moment due to the intensity of my job. I was extremely exhausted if I spoke for long periods and my mind and mouth would shut down! I was very grateful that his family paid for all out accommodation etc, I just literally needed some spending money.

The thing is, when you are chronically ill, you do not HAVE spending money! I ended up having to borrow it from my partner and really struggled to pay it back until I was let off the final chunk of it. It was a really stressful time. The flight was not the best but I got through it.

The meals were the hardest thing I found. It was noisy - I love kids by the way - but with 12 people talking all at once or over each other it was a lot to take in, especially in a busy restaurant in a busy tourist location.

There’s one thing that would take the edge off my vestibular disorder and that was Gin and Tonics!

EVERYONE is different when it comes to alcohol. Some feel absolutely horrendous, for others, like me, it takes the edge off.

The problem with drinking too much is the next day you will STILL have the hangover from hell plus some! I do not judge anyone that wants to enjoy a drink when they are on holiday!

Each to their own.

A large Gin and Tonic literally got me through those big meals and I had fun too. I won’t lie, I burnt out very quickly and there were a few occasions where I had to even skip the family meal all together or go home early as I just could not handle all the noise, vestibular movement etc.

The other hard thing is, his family were aware of my illness and very supportive, but at the same time I knew from my partner they worried about the stress it was causing him too.

Basically, you are sick and you KNOW people think you are a burden on their loved one. HOW will you EVER feel comfortable being around these people KNOWING that? This brought back the feelings of guilt, shame and embarrassment. I remember feeling incredulous when he told me that his parents were concerned for him. I was the one that was sick I instantly thought, but then for the first time in months, I really looked outwards at him and saw the weariness in his eyes, that he rarely laughed anymore and his moods had started to get low.

WHY couldn’t I just get it together? WHY could I just not work a normal job? WHY WHY WHY WHY WHY?????

It was through times like these, I did think to myself, if this continues and I am still dizzy 24/7 in a year's time, I want out. I will no longer have to smile and lie and say I’m ok, I will no longer have to lie when really I want to tell them that really I just want to lay down, sleep and never wake up.

I just want to lay down and sleep, block it all out.

I know now that I was doing the best I could during those holidays. I would smile and push myself to my limits. I also want you to know that I DID have fun! Playing with the kids in the pool really takes your mind or constantly being sick or focusing on your dizziness.

We would drop things at the bottom of the pool and all dive down to get them, we also had a Gopro and had hours of fun filming ourselves under water playing.

Afterwards, yep……. I could have slept for a week……. But was it worth it? YES!!!

The sun, having lunch on the beach, late evening walks along the promenade, delicious food and carefree kids. YES, it was very difficult at times, YES I had to recover after flying as it really took it out of me, YES you can feel like a burden when you need to leave a family meal early as you are extremely dizzy and feel so weak you just know you need bed.

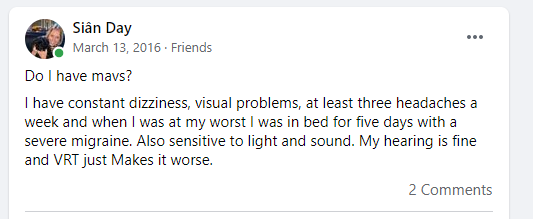
But I pushed myself and overall the sun, sea and sand did me the world of good. It showed me what I was truly capable of.

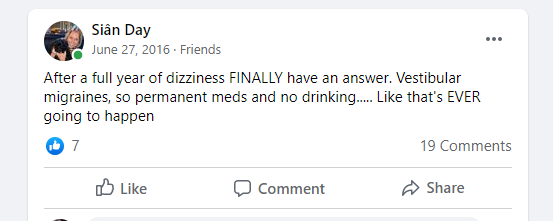
**Holiday Tips** - try to plan what you want to do and where you want to go in advance giving yourself adequate recuperation time afterwards. So for a snorkelling trip, you may need at least 2 days to recover from a 30 minute casual swim for example.

Bring a BIG hat! Anytime I forgot it, I had a migraine! Also DECENT sunglasses are a must. I had cheap £30 ones and my friend had £250 pound ones. I have always refused to spend an extortionate amount of money on sunglasses that I am either likely to scratch or lose within a week! But her sunglasses when I tried them on were a game changer! I did not squint once whilst wearing them, a good sign they are worth their weight in gold!

**June 2016 - Vestibular Migraine Diagnosis**

( Putting the pieces together, did I have vestibular migraines? Early Facebook posts! )





It’s here!!! I was finally about to meet Dr Barry Seemungal. He is one of the top neurologists in London.

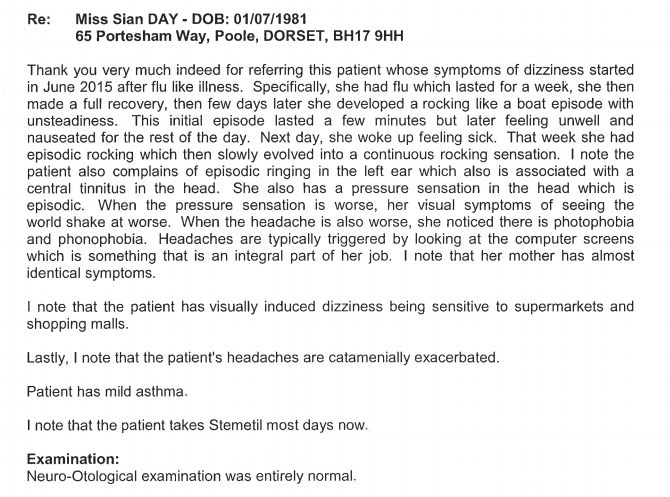
I had been waiting for a year to be correctly diagnosed. I had to argue with doctors, change them a few times and literally try not to cry and tell them I could NOT do this any longer. The moment I DID cry, they would look at me sympathetically and tell me it looked like it was just anxiety and then the vicious diagnosis circle would continue.

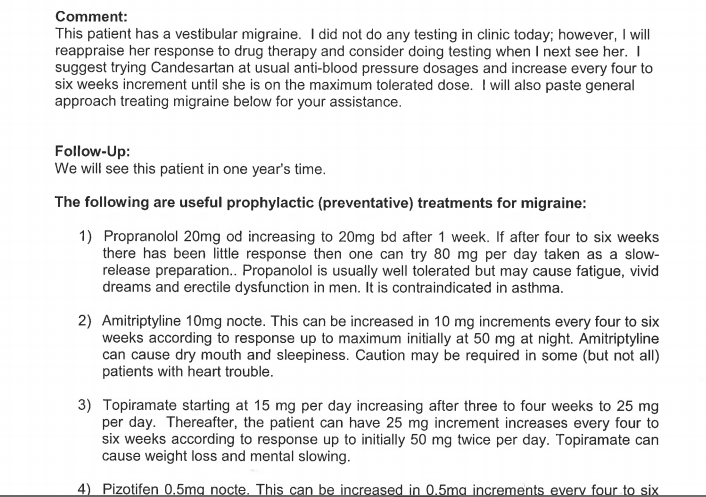
At my appointment with him,we went through all my symptoms. He also looked at all my blood tests, scan results and tested me with the Epley maneuver to see if I had an inner ear condition and if this would treat it.

This was laughable as after a year feeling constantly dizzy, I had already tried the Epley maneuver countless times at home using Youtube videos and neurologists that talked you through how to do it.

Thanks to the migraines that had been hovering in the background since this started and a family history of migraines he was able to diagnose me within the hour. I was completely unaware that when I was a teen the flashing lights I would get that made it impossible to study in class were migraines with aura! SO much makes sense now!!

Here are his findings.







It was official. I had vestibular migraines.

Something odd happened then. As I sat facing him, already knowing that this was highly likely to be my diagnosis anyway and already half expecting it, I burst into tears and I could NOT stop!

It was a mixture of relief, but also knowing that this was now a chronic condition that would not just go away by itself and it is one I would have for the rest of my life. At least with Labyrinthitis I hoped with enough vestibular therapy, I would make a full recovery.

So I sat in front of him and just started bawling, like really bawling, The type where they have to run out of the room and grab more tissue. He became quite alarmed but managed to calm me down and I just kept thanking him and saying sorry at the same time.

What a strange feeling, a mixture of elation and also fear of what was to come and to know there was something wrong with my brain and it would never function like it used to again.

I remember calling my partner with relief. I was finally diagnosed and also I could start on medication. Back then, I truly believed if I just took the right medication, then my dizziness would stop within days………… wow, how much I was yet to learn.

**October 2016**

Now here is what you need to know about medication. What MAY not work for you WILL work for others.

I was so sensitive to medication that when I started through his recommended list, I could barely tolerate it for a week let alone the 6 weeks that I really needed to take it to make an impact.

The fact is, I was working too every day and I was so spaced out half the time that I couldn't function. I did not have the luxury of putting my feet up and riding the dizzy waves through, I needed money to live on, for clothes etc. The medication gave me so many side effects,and I was so sensitive to them that I had to give up after 3-4 weeks as they just made me feel so much worse.

It’s SO important for you to know that now I wish I had given them more time. I have spoken to countless people that it has worked for and was a COMPLETE game changer for them when it came to their healing and getting back on their feet.

But I NEEDED to be with it to handle my job and I put that first. I now wish that with my ESA, when it failed I HAD appealed as I was later informed that nearly everyone failed unless they appealed, so please, if you are really sick and mostly housebound and you get turned down, especially in the UK, APPEAL!

I came off all medication in the next 4-5 months and only kept stemetil to take the edge off. I WAS getting better thanks to lowering my stress levels and the constant walking every day.

I am certain that if I lived in the country with not much vestibular distraction, I would not have recovered as fast. But for me, the moment I left my house I was in central London, with one of the busiest roads in the city!

YES, I still felt dizzy everyday, YES I still felt exhausted, YES my depression and anxiety and insomnia were STILL there but I did notice when it came to walking, I WAS improving……. I started to have hope that even without the meds, I MIGHT just make it through.

I had also gone back to the vestibular exercises I had found on YouTube. I NOW know that you really need a specialist to give you specific exercises based on your condition but at the time I just did what I could out of desperation.

The exhaustion I felt after this was so intense, to this day I feel that only someone with chronic fatigue would understand it. I could barely lift my arm, it was a led weight. It also took EVERYTHING I had to get out of bed each day and to just speak! It was such an effort.

( I want you to know that even after 5 years and functioning pretty much at full capacity with NO dizziness throughout the day, that if I over do it, I will feel completely, utterly exhausted where I will be bedridden for at least 3 days and that’s why you need to learn to pace yourself and not to run before you can walk, or at the very least do NOT do an extra 10 minutes walking, exercising if you feel you can push yourself that little bit further.)

Now, the last 2-3 months I had one symptom that for me will remind me of how bad things actually got.

Jelly legs. They are back with a vengeance! The fatigue got so intense that I literally could not walk. I could hardly stand. I think this was one of the lowest periods of my life. The weakness, the exhaustion, the pushing myself, the trying to get back to normal as quickly as possible. Trying to hold a job together when the depression was kicking in, the DIY vestibular therapy… the battle is endless

So even though my vision had started to slowly improve alongside the dizziness, the longer I walked for or the more stress I was under, the more my body would crash and oh my god did it crash.

Years later, I asked my partner how bad it REALLY was back then, as I had tried to block most of it out and I remember saying, ‘was it REALLY that bad?’ And I remember the exasperated look on his face and he replied, ‘yes, it was REALLY that bad.’

I also struggled to go from being a super sporty person in the past, to feeling so incapable now. I just could not believe this was my life now.

I started to realise my heightened anxiety would also worsen the symptoms of jelly legs. Looking back I had NO rest whilst I was going through all of this. I was non stop all the time as a social media manager as it’s the only job I could do from home and I needed money and support!

So although I felt that over time my BODY was getting better and I WAS starting to make a recovery, my mental health started to decline and it was so subtle, it was scary.

I found this email I had written for this month after my diagnosis.

**‘Imagine you had a career goal, ok so things aren't perfect in your current job but they are paving the way forward for your ultimate dream job, as a travel writer. You have good friends in your office, a good salary with enough bonus to send you jet tripping overseas to an exotic location and a busy social life. And then, you get sick.**

**At first it's an overwhelming feeling of nausea, which then turns into strong dizzy patches that leave you clinging to walls. You carry on and try to commute into work until it becomes so overwhelming you're jumping off the tube 8 stops too early to stop yourself from being sick on the train.**

**To cut a long story short you're diagnosed as having labyrinthitis, a year later chronic vestibular migraines.**

**You have now been suffering from them for 15 months. Your life is a shell of what it was like before. You gave up your career to luckily find a home based job and you are now living with your partner in a large complex.**

**Your social life is now non existent. The exhaustion, dizziness is overwhelming. You have good days of course where you can go out and have a drink, but it takes days to recover from it. The most you can manage is walking to the high street and back for a coffee.**

**You wake up everyday around 9.30 and walk into the living room and start working. As grateful as you are for the flat and your partner supporting you, you can't help feel your life is slipping by. After 6 months of waking up and working in the same dull living room, where your only view is more brick walls and windows, you start to feel down.**

**You think you've done very well up to this point, always thinking positively, going out whenever you can, but feeling trapped in this flat is more like a prison. You want others to understand but they can't. This is an invisible illness. Catch me up the high street and I'm fully made up, dressed fine and you wouldn't have a clue that I'm mainly house bound.**

**You start feeling anxious and depressed. You can't join the gym now your one escape as now you have issues with walking. So you have to stay confined in your small grey flat and wait for your partner to come home, with his full social life, listen to his after work events and beautiful lunches with his friends.**

**Then he goes to the gym every evening for 2 hours and all the while you are trying to smile, act like you're coping. Until one day you start to feel resentment. Your partner has done EVERYTHING in his power to care and love you, but he will never understand what it's like to lose everything.**

**I now work and feel what's the point, to work for what? I can't really go anywhere at the moment, I can go to the same high street, to the same coffee shops and sit and read, then go back to the grey living room where I spend 12 of my waking hours.**

**I smile in photos, I make the most of opportunities, but I'm grieving for what I had before, for my friends, it's lonely and I'll NEVER get it back.’**

**November 2016 Depression**

It’s still so odd, although my body is starting to very slowly recover, I am still going downhill rapidly when it comes to my mental health. I feel this is because there is one HUGE step that I have still to overcome, acceptance. I have a chronic illness, and it is out of my hands.

This WHOLE time I have been like a machine, crying it out when it gets too much and then getting up the next day to do it all again, walk like I am a robot, push harder, faster, push, push, push, get in, work, sleep, do it all again, push, push push!

Get better faster! That’s what is expected of you! People are tired of you now, WHY can’t I just get better???

I managed to walk 4 miles this month around Chelsea and it took me days to recover. This was a massive achievement for me! But I was still far too dizzy to function in my old career, let alone pursue a new one. I had soooooo many limitations. I was starting to realise that this could be my new normal and I was going under. I was more anxious, my insomnia worsened, I lost my appetite and the migraines would rev up again.

The work was killing me, I knew I HAD to stop! My brain was fried but I had no choice. I started to seek out help and found a free counselling service in Hammersmith. I was booked in for December.

Talking really helped me through the worst of it but I still needed my Facebook migraine groups as at the end of the day, the counselor could only listen.

She had no experience with someone with a chronic illness and didn’t really understand the loss. It put a bandaid on a wound that could be torn apart at any time but at least I was trying to find a way to heal emotionally.

In the meantime, I was getting desperate to try one of my last options when it came to medication, Flunarizine.

( **Flunarizine** is a type of drug known as a calcium channel blocker. Calcium channel blockers are medicines that are most often used to reduce blood pressure or treat certain heart conditions. **Flunarizine** is not licensed in the UK, and so its use for preventing migraine is 'unlicensed' )

I had read a few stories about it being a miracle drug when it came to vestibular issues too from other people and pinned all my hopes on it. The strain of Christmas was beginning to show again and I started to get very sick again.

The most terrible thing about this illness is you take ten steps forward and then can come crashing back within days. It’s like it just will not release its grip on me and claws me back in no matter how hard I fight it.

The counselling gave me a bit of a push to really look back into the med route again. I HAD to get a grip on it! I decided to chase up my neuro again about the last med that I thought may be my miracle cure so I reached back out to them.

**‘Hi Carol,**

**I have an issue at my doctors regarding the medication that was advised by Dr Sanjeev.**

**It looks like I have tried Topiramate before and I reacted very badly to it so I do not wish to take this or any anti-depression seizure meds again which leaves the calcium channel med Flunarizine which is also used for vestibular disorders but my doctor said I have to get that from a specialist like you so is this possible?**

**I am currently left without a preventative and I really would like to get started on one as I am just not getting better.**

**Sian**

**Hi Team,**

**I have started to get every sick again, dizziness and I am trying to get hold of the preventative suggested by Dr Sanjeev the Flurazine but my doctor said only a specialist can supply it so I am back to you guys.**

**Please can you tell me how to get this ASAP as my symptoms are getting worse, even on sumatriptan.**

Now it was just the matter of waiting.

**December - Under eye fillers**

Is anyone sick and tired of people telling you that you look tired or unwell? This I felt actually hindered my recovery to the point I would look in the mirror each morning and become OBSESSED with how dark I was under my eyes and if it related to how dizzy I would feel that day.

I must admit, in the past I was always rather judgemental to people that had any kind of cosmetic surgery. Maybe because most of the results had been over inflated lips or frozen faces and less that subtle compared to today's methods.

So I would never have thought in a million years I would EVER have anything done but my eyes were horrendous! Even on a GOOD day I was tired of random people telling me in the nicest possible way I ‘looked peaky’ or was I ‘coming down with anything?’. Obviously I was sick, but I didn’t want to look in the mirror every morning and have someone looking back at me that looked sick. It really affected my self esteem and actually made me feel worse, so I started to research tear trough flyers over the next few months.

Obviously the thought of needles going anyway near my eyes honestly terrified me, and then came the pain factor. But looking in the mirror and seeing someone that looked fairly healthy reflected back to me became too big of an obsession not to take this matter further.

How ironic that it’s already hard enough having an invisible illness yet here I was trying to make it look MORE invisible to the naked eye?

I found a Dr to do the procedure and I remember I was absolutely terrified on the day, but the Dr instantly put me at ease. He didn’t rush anything and sat me down and talked through my concerns. He told me that he would be using a numbing cream and also a cold metal press to help minimise bruising. He was so relaxed and happy that I felt comfortable and even managed to have a laugh with him.

And ironically, considering I had built it up for months, I hardly felt a thing and definitely no pain, more like a scratch and that was only once too.

The results speak for themselves. It has massively increased my confidence and it has done amazing things for me mentally to look in the mirror and not look so exhausted and ill. I was trying to heal as best I could and move on from my past, I wanted to see that reflected on my face too. I wanted to get as far away from this illness as possible!

I didn’t care about fine lines, wrinkles, I just didn’t want to look sick or tired anymore.

I now realise that lot’s of people have had surgery around me but you would never know as the results are subtle and more of a ‘refresh’ look rather than trying to wind back the clock and look 10 years younger.

It did take a few sessions to get the results I wanted but it honestly was one of the best things I have ever done!

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**March 2017 The Big Night Out**

My friend is visiting from Finland. I usually meet her in my local coffee shop where I go every day to get out the house and get some fresh air. She wants to go to a bar locally and I am really worried about it as I still get dizzy and off balance and to this DAY I find it very hard to stand stationary for over a few minutes as I start to sway and I am off kilter.

But being an ex party girl myself through and through, I take the chance.

I wear flat black ankle boots and have a Jack Daniels and coke and head which takes the edge of my creeping anxiety and head out to meet her in the bar. GOD it’s hard! The lights are so bright, so many people talking and no seats! I stand up and sway until I have to hold on to the bar until a man gives me his seat out of concern for the ‘drunk lady’ and I have to explain that I actually have a vestibular disorder, I’m not drunk!!

As the night wears on, a funny thing happens. It’s a really fun international crowd and it is a buzzing environment and everyone is smiling and laughing. I actually FORGET for a moment I am ill or dizzy, I am not noticing my jelly legs and my wobbling either! I am so distracted to be out again with my best friend that I feel a surge of adrenaline and happiness.

It doesn’t last though. Within a few hours, I feel so exhausted I have to get an Uber home. I can barely take off my boots or jeans, not due to the alcohol like when I was in my twenties lol, but because I have NO energy left in my body. I sleep with my makeup on and pass out for the night.

**The Next Day…..**

I can hardly move. I do not have a headache but the tinnitus is loud this morning. I am sooooooo shattered from standing up in a bar for 3 hours ( and half that time sitting! ) that I can hardly lift my arm. It takes EVERYTHING I have to pull myself upright in bed. I am completely spent, far too exhausted to talk.

Literally every trigger going was in that bar. The noise, the people, the constant talking, the lights, the lot! But was it worth it??

God damn right it was! For a few short minutes that evening I felt normal again almost. I felt like I had before this happened when I had a really active social life and would laugh and dance and meet new people. I forgot what it was like to feel happy and alive.

It took me at least 4-5 days to recover, but I was ready to do it all again a few weeks later and on it went! I found that the more I put myself in this busy, hectic environment, the faster my vestibular system adjusted to it and so did my tolerance to what I could handle.

8 months later I was able to go to a bar and stand up for a WHOLE hour! 5 years later I could go to a club and dance for hours.

But in the meantime, I was back in my flat, back to feeling dizzy and exhausted trying to hold together a job that I really should not have been doing, and the constant stress about my relationships and money and just basic survival would bring me each time again and again.

**July 2017 St Marys**

I hit the 2 year mark. I can’t believe I am here. It’s been two years of constant dizziness, literally every day I will ALWAYS have some vision defect or balance issue BUT…… I am definitely on the road to recovery!

I now have days where the dizziness is milder and where I can do a lot more. I may have a good full 4 days of just mild dizziness! Can you even imagine?? I truly believe this is all down to me consistently waking every day and staying active over the last 2 years 100 percent!

I am often asked HOW do you know you are getting better when you have so many relapses, some worse than before! My answer is the same as my neuro. In general, YES I will get relapses but then tend to be further apart.

What do I consider to be a relapse? For me, it will be housebound, bedridden, days where I feel I can’t move. Complete utter exhaustion, anxiety through the roof and extreme dizziness and loss of balance.

On a daily basis I have had what my neuro thinks is PPPD which means Persistent postural-perceptual dizziness. It’s a common cause of chronic (long-lasting) dizziness. It is usually treatable, especially if it is diagnosed early. Usually, **PPPD** is triggered by a prolonged episode of vertigo or dizziness.

This made complete sense to me as it took a full year to get my diagnosis so I was not aware in the early stage how important things like vestibular therapy were! I avoided it like the plague as it made me feel worse!

I STILL wanted to conquer my daily dizziness as although it was no way near as severe, if a car shot past me out of the corner of my eye, I would still get very off balanced and also simple things like stepping onto an escalator often were a complete mission! I knew I had to take another step up if In wanted to function as independently as I possibly could. I knew I had to ‘up my game’ to get back to a more CONSISTENT functioning level.

After all, what’s the point of going paddle boarding ( Which I managed ) if after I relapsed and was bedridden again for days? I knew I had to push myself more and that little 15-20 minute daily walk was NOT going to do it.

I had tried VRT in the early stages of this illness but I believe I was soooo dizzy and my vestibular system was sooooooo out of whack that it actually made me worse! This is often the case and why people don’t give VRT a proper chance BUT…… I returned to it as I started to get stronger and I was determined to up my game and cut down on the number of my bad dizzy days!

My neuro had referred me to get VT months ago and now the day was finally here.

Upon arriving at the gym in St Marys, I felt like an idiot. There were so many people with OBVIOUS injuries, learning to walk again and I was the only one that looked COMPLETELY fine.

I remembered a conversation at the peak of my symptoms with a professional snowboarder that had her leg amputated years before. I was embarrassed at the time meeting her as I was still very sick and could not stand up straight for more than 15 minutes without things moving and me having to hold on to something. We were at a charity event and she could see I was dizzy as I was clinging on to the table with food on it for dear life and rocking whilst I spoke to her and we had a heart to heart. At the end of it, she made me feel so much better about the guilt I carried with my condition.

I felt that compared to her, I had no right to say a thing or confide to her about how hard I felt, but when I explained the debilitating symptoms, dizzy 24/7, learning to walk again properly which would end up taking over 2 years, anxiety, insomnia, depression, regular excruciating migraine attacks, not being able to cross roads etc, losing my career, home, the lot, she actually turned round to me and I will never forget this, and kindly said, ‘At least I didn’t have the neurological issues that you had. I have learnt to get my life back, continue snowboarding and to be self sufficient and continue my career. I don’t think I could have handled all that.’

It really changed things for me. I would never admit it at the time but at my very worst, after 15 months of being dizzy and seeing double, the floor moving or dropping between my feet, suffering with an invisible illness and trapped in a body that looked fine, I often thought at my lowest, at least if I lost an arm instead of this or a leg, I would be able to learn to walk again, and my head would feel FINE! No more rocking, dizziness, unable to cross roads, spinning attacks, nausea, feeling like I will fall in front of a train when I walk on the platform, to be able to keep my career I had worked so hard for and use computers again, hold conversations again with people, continue to do sports etc……. HAVE A LIFE!

To have a CLEAR head! NO more dizziness! NO more dizziness 24/7 for YEARS!

I didn’t want to be trapped in this body anymore. And I was willing to work HARD to get myself out of it. So I started my training with 2 therapists. I could see other patients watching me trying to work out why I was there, but they could soon see something was wrong after my first exercise.

The aim with my VT was to do VERY simple exercises and time how long I felt dizzy for afterwards, Overtime and weekly exercises, I should start to adjust to these exercises and feel less dizzy.

They gave me a small, hard red rubber ball that fitted in my palm and all I had to do was pass it from hand to hand…… easy right? I then had to throw it higher and higher keeping my eyes tracked on the ball as I passed it from hand to hand, not taking my eyes off of it for a moment.

Literally, within a minute, I felt so dizzy I thought I was going to throw up. I had to sit down suddenly and the chair was rocking. I had my head in my knees whilst they ran to get me a glass of water and I was pale and shaking. They thought I was going to faint! I was COMPLETELY exhausted from a 2 minute exercise!

My back was actually damp from the exertion and I had a cold sweat. - ( What IS it about the sweats we get with this too?? Waking up in the night and your T-Shirt is SOAKED through??)

When I tried to stand, I fell into the Vestibular therapist and then she had to hold my arm whilst I tried to do the rest of the exercises.

Needless to say, I went home and slept for days! Only people that have this can understand the COMPLETE exhaustion this can cause. When you feel like crying as you need the toilet but you know you can’t get off the sofa from sheer exhaustion, and simply lifting your head takes everything you have got……. and then you roll off the sofa onto the floor army style and crawl to the bathroom on your hands and knees. Yep…… THAT kind of exhaustion!

Washing my hair? Forget it! Drying it? You must be joking!

I DID push on though and did these exercises daily and over the next few months I really excelled at them until I got to the point where I only felt dizzy for maybe 30/40 seconds after an exercise, not 5 minutes solid!!

I felt like maybe my health COULD improve to a level I had never dreamed possible! I felt a glimmer of hope…….. But as my BODY started to adjust and heal, the depression came back with a vengeance.

**October 2017 - Severe depression**

**( Please note this chapter will speak about feeling suicidal which can be a trigger to some. Please skip this if you need too and know that I DID come through it! )**

Oh no, we are back here again. To be honest, it never truly went away.

The scary thing about depression is how it creeps up on you. I felt numb, devoid of emotion. I knew it was getting very severe over the last few months when I just wanted to sleep all the time as it was better than being awake.

I had come so far with my fitness and my walking routine, the vestibular therapy, even accepting this was how it was going to be, but I was truly and utterly exhausted from the battle of it all. You need to remember that I had not truly had a break from work since my diagnosis. I felt like I was working to live, yet not actually living.

The 2 years of monotonous routine, the dark living room, working from an ironing board on a laptop, hours on my phone, the migraines, the dizziness, the relapses, the anxiety, insomnia, jelly legs, the realisation that I will ALWAYS have to struggle to make ends meet for the rest of my life, the fact that I had lost close friends, that I felt so lonely truly started to hit home.

A night out or a holiday did not hide the fact that I was so burnt out, that I could relapse at any time ( And I did, often! ) I just could not deal with it anymore, and even more, I was tired of feeling like I was such a burden.

I was tired of these moments of brief respite where I got my hopes up that I CAN have a normal life again, for it to come crashing down a week later and turn me into a tear filled, bedridden emotional wreck.

I was also embarrassed, I felt a lot of shame that I just was not progressing as fast as I felt I should have, and I honestly felt back then that I would NEVER get better.

I wish I could be stronger like my dad. It’s only now I realise that reaching out and asking for help was actually one of the bravest things I have ever truly done in my life.

I have had suicidal thoughts before after losing my dad when I was 19 to cancer. Before, after such a tragic loss, I knew I could not put my family through the loss again so I held on. And yes, I had often had suicidal thoughts over the last 2 years at my lowest times throughout this illness, but I had also somehow managed to claw my way back out of that pit of despair.

But this time, it was different. It got so bad I realised I didn’t care if my loved ones would be upset without me or not, I wanted out. It was only when I started to actually think about how I would do it I began to get really scared.

I felt like I could not be alone with myself anymore! As a voice somewhere deep inside me would tell me that I didn’t have to live like this anymore and it was OK to give up and just sleep. I felt I was no longer in control of my scary thoughts and the depression had such a hold on me, I truly felt I couldn’t trust myself.

It was terrifying.

It got so severe that I honestly did not trust myself being alone when I was down and I am no longer ashamed to admit it now but I remember one day as I was very sick and swaying on the TFL line to visit the doctor, for a split second I looked at the track and yes, you can just imagine what I thought.

I was absolutely petrified. I have always felt in control of these low dark moods in the way I could lift my way back out of them, but the spur of the moment, ‘just end it’ ones I was not. I felt like I was going mad. I needed help and fast.

Now, I knew my partner at the time was on breaking point. He was the main person I confided in, and now I had to wait until he got home to drop another bombshell on him.

I felt suicidal, to the point I actually wanted to harm myself.

I remember telling him when he came back from another crazy long shift and I could see how tired he was when he walked in shattered, dropped his bag and walked into the kitchen where I followed him and just dropped this bomb. It’s like I just HAD to get it out. I’ve been feeling this way for weeks now and I was scared. His face just dropped, and he hugged me and told me it would be OK and we would get help but I knew right then that something had broken and it wasn’t just me, it was us.

How much more of this could he take?

He’d had two years of this, I was tired of being a burden on him, I had no friends around at the time that lived near me that truly understood what was going on, they just thought I had vertigo and headaches. I obviously had one or two that would make drop ins when they could every other week bow and again, but most of them did not live in London. He really was my number one support and I off-loaded mainly on him. We couldn't carry on like this.

( I have spoken to people married for years that have supported partners through this and stayed together and at the end of the day, I just believe if you are meant to be together and you have found the right one, you will be, as simple as that.

We were not meant to be. In fact, we are both with who we are MEANT to be with now, truly happy and I wish him all the best and will forever be grateful for the support he showed me during this time, I could not do it without him, no way! He even put me on his medical cover so that I could have sinus surgery and get the best neuros possible. I would definitely go as far as saying I would not even BE here if it was not for him, there is no way I would have been able to make it through all this and it’s better to think if the fun and goofy times we had through the last few years and that we did really love and care for each other.

It’s funny but if I had to do it all again, I feel it would have been easier to be single than have to hide, or cover up emotions and also not to feel guilty that you cannot be the ‘normal’ partner that they want you to be or you feel they deserve.

I have felt enough guilt over the last few years to last a lifetime, no more!

That’s just how I felt at the time. This was the beginning of the end for us and I knew it. My symptoms were constant, my needs were constant, the mental health and anxiety issues were always there lurking in the background no matter how many times we travelled, laughed or tried to pretend it wasn’t.)

After that bombshell, I did manage to find a proper therapist and even she cried which at the time helped as it made me feel better that someone understood me and had empathy.

It felt so good to cry and release it, sob and feel free to do so without ‘freaking anyone out’ that you are losing it. I had tried to hold it together for so long and mostly broke down in the bath as no one could really see me and just really let it out. To this day I still do that if I need too! I know it may give me a migraine afterwards but it truly helps I swear! Better out than in!

The important thing to know is, to be able to talk to someone again that offered solutions to anxiety etc really helped me. I just let it all out and saw her every week for around 6 weeks and it really helped me to keep going.

NEVER underestimate the good a therapist can do and also, I would advise you to search one out before you get to a place like me, stay on top of your emotions, talk to loved ones openly about how you feel or even a doctor, even our Facebook support group but it is VITAL you talk to someone.

**November Flunarizine 2017**

It was time to give medication another shot. Yes I was getting so much better with my vestibular exercises, but my migraines had mutated into horrendous 6 day outbreaks and were literally like the back of my skull was being crushed in a vice.

I was STILL having visual issues and could not see very clearly and things would jump about and I could not really focus on anything clearly for more than a few seconds, like in the early days again.

I had multiple tests at the London eye hospital and at specialist opticians but they all confirmed it was nothing to do with my eye health but the migraines causing the vestibular dizziness so I HAD to get it under control.

I chose to return to the med route and try a new preventative. I had heard of Flunarizine on a Facebook chat and it literally was the medication that ‘saved’ this person. You may notice I do not cover medications in here and there’s a simple reason for that.

When you have this condition, you spend hours, weeks, months, years of researching someone else's 'miracle drug’ in the hope that just MAYBE…...it could be your miracle drug too.

After having this for so long, and what we now believe was PPPD, the thought of living some kind of ‘normality’ seemed far fetched to me. But as the vestibular exercises started to work, I had hope for the FIRST time ever, that maybe, just MAYBE there was a way out of this hell hole.

And the answers often lay in the Facebook migraine support groups, for the elusive ‘survivors’ that would drop back in a few times a year to confirm they were doing OK, they were living their life again, to have hope that WE can get better too! And then they were off…...

Can you BLAME them? Who on earth would want to revisit this every day of their damned life!? That’s why when we started our Facebook vestibular migraine group which now has over 6,800 members, a few of us still check in and update the group regularly as it is so IMPORTANT for people to know that you can get better and learn to live a ‘new’ you.

A MASSIVE thankyou to our well known and loved admins Chloe, Deborah and Gemma for keeping this going as it takes so much work and god knows I am not in there nearly as much as I should be!

So when it comes to medication, as I said before, what MAY work for me may NOT work for you and vice versa. If I scared the crap out of you with horror stories of a certain medication that made me feel worse, more anxious etc - I’m very med sensitive - it could put you off trialing it yourself and it could be THAT medication, that MIRACLE that gives you your life back.

And that’s why I do not cover in detail all the medications I have tried.

Flunarizine is a calcium channel blocker. It is believed it works by ‘inhibiting the movement of calcium ions across the cell membranes. This prevents mechanical contraction of the muscle wall of the artery.’ in tech speak lol.

I was particularly nervous about this medication as it did have links to parkinson's disease and also could cause very low moods, which was very close to home to me after only being there two months ago, but at this stage and with the agonising 6 day migraines and my failed earlier attempts working down my list of prevantiatives,, this was the next stop.

I would be closely monitored for my moods too. I remember I did not feel any side effects at first, in fact, only a few days in I remember walking out of my house and looking at a Red car parked outside and stopped suddenly.

It was not moving, it was not bouncing about. If I looked at it for a few seconds, I could STILL focus on it WITHOUT it jumping around! I could see the watermarks that the rain the night before had left dulling the Redness in places and I was mesmerised. It was like seeing again properly for the first time in years. It was a miracle.

Now folks, I would love to tell you that this was my final resolution and things got better from here on in but in fact, after another few months on this medication, I DID notice a severe drop in my moods to the point I would feel like randomly bursting out in tears in the middle of the street…. Something I can’t recall I have ever done, and then the depression started to come back with such vengeance that I was very concerned for my mental health again, and for this reason, my neuro and I decided it would be better to come off this particular medication.

So YES, I really did think it was my miracle drug, yes my vision improved greatly, NO, for ME at least, it was definitely not suitable in the long run, but I know others that SWEAR by it and that are back to functioning at an almost normal rate.

**April 2018 Surf Trip**

It’s finally here…. The surf trip.

I first started surfing when I was 23 in France and was instantly hooked. Over the years since, I booked multiple surf holidays in schools in Portugal and when I lived in Australia I would surf almost daily on Bondi beach for well over 16 months.

There was one odd thing I recall, looking back at my time in Sydney in 2008. I remember I was terrified of the bigger waves and paddling out back so I used to surf on sand bars where the water was shallow and I could push off.

I was always embarrassed that although I could turn left and rights and my balance on my longboard was really really good, I ran out of energy so quickly that I had a few really bad experiences in deep water with bigger waves where I simply could NOT get back on my board and paddle to safety so to speak.

It was this sheer and utter exhaustion that would take over that NO one understood at the time, not even me, but now I believed it to be the point where my vestibular migraines ramped up a LOT.

I can’t explain how scary it was to be out at sea on a longboard, seeing big sets come in and not managing to duck dive as I was on a 8ft board. I would have to eskimo roll as we call it, where you grip the board and turn it upside down so you are underwater facing up and looking at your board and holding onto it for dear life whilst the bigger waves roll over. You then have to flip your board over quickly before the next wave hits and clamber back on it and paddle for dear life to get out of the way for the next set!

I remember at one point in Portugal, being forced to do 3 Eskimo rolls in a row one after the other, and afterwards, I was so exhausted I barely made it back to shore and spent the next 3 days of my 7 day surf trip in bed recovering.

I just could not understand my fear, OR my exhaustion and I needed strength to get me out of difficult situations when I needed it! I now know I was likely to be suffering from vestibular migraines and was dealing with chronic fatigue, so even after my back muscles developed and I was at my peak fitness wise surfing at least 3-4 days a week for 16 months, I STILL suffered from extreme exhaustion.

I remember when I hit 28 I was walking along Bondi beach when everything began to take on a really surreal element, where it was like I was in a dream and not really present and floating and felt completely ungrounded. I now know this to be called derealisation.

Below are the symptoms.

* Feelings that you're an outside observer of your thoughts, feelings, your body or parts of your body — for example, as if you were floating in air above yourself
* Feeling like a robot or that you're not in control of your speech or movements
* The sense that your body, legs or arms appear distorted, enlarged or shrunken, or that your head is wrapped in cotton
* Emotional or physical numbness of your senses or responses to the world around you
* A sense that your memories lack emotion, and that they may or may not be your own memories

Now I look back and think it’s a miracle I accomplished what I did and carried on regardless, even with the fatigue. Sometimes, the less you know the better! But even though I was dealing with derealisation back then and chronic exhaustion, the vertigo and 24/7 dizziness still had not hit.

I find now I beat myself up less about my fear now of just paddling ‘out back’ and catching a wave. I’ve only done it a few times in surf schools and I was so weak after paddling out back, that I had no energy left to catch the wave itself, the surf instructor would push me off onto the wave and once I was up, I was FINE! Left and rights and very confident. Even the instructors were confused!

Since this illness started I had ONE wish. To catch a wave again. I even had a vision board next to my bed with a blonde woman surfing, I think it was from a Tampax ad in a magazine lol, but I would go to sleep with it and wake to it EVERY morning determined that ONE day, I would be surfing again.

I had already cancelled a surf trip 6 months previously as I had a massive relapse and I realised there was no WAY I would be able to travel the 10 hour train journey etc to get to Newquay and hire a board.

Back then I was devastated when I had to call the surf school and cancel my accommodation. I even started to get really depressed again and the jelly legs came back. I now think that I got so sick from the stress and pressure of not cancelling the trip as I would lose money and all the pressure of ‘would even be able to balance and stand up again on a moving board!’ that it made my symptoms worse.

But now it was game on! I was on my way to Newquay and this time, NOTHING was going to stop me.

The trip took over 10 hours with a few changes in between and it was really exhausting. By the time I arrived in the early evening I got an Uber to my Air B n B and checked in for the next week. I said a quick hi to the Owner who was also a surfer with a gorgeous bulldog and passed out for the night.

The next day I was exhausted and there had been snow on the beach just a few days before. I went to the surf shop and hired an 8 ft board and booties which are rubber thermal like socks to keep your feet warm but I could not grip to the board properly, it felt alien to me so I got rid of them and let my feet turn Blue.

I was not about to let cold feet stop my 3 year game plan!

By the time I made the 8 minute walk to the beach, I literally had nothing left in me. But I waded into the water and stood up on a sandbar and waited for a small 1-2 ft wave. I saw one heading my way and at the last moment I pushed off and lept on my board and caught a tiny clean wave into shore.

The moment was pure elation. I could STILL stand and keep my balance after nearly 5 years without surfing! But once the adrenalin had left my system, a wave of exhaustion came over me so hard all in all I ended up in the water for 20 minutes at best and headed home. That was me done for the night. 3 years waiting for this moment for 20 minutes of surfing lol!

This carried on and I took a few days off in between a really hard stretch when on a windy day I dragged my 8ft board on a 20 minute walk down Fistral beach until I could surf between the flags. The sand was thick and the shells were sharp and the current so strong it was the most exhausting day I have ever had in my 3 year illness so far. My legs were like jelly and I felt like crying a few times on my way there as I realised how truly ‘f#cked my body really was. It was so weak and I knew by doing this little stint that I would pay for it later but mind over matter took hold of me that day and I pushed on.

I waded in against the cold water and current until I managed to get to a sand bar where I could stand and pushed off on a small wave. As it got closer to the beach it reformed into a bigger wave and I surfed a longer left into the beach and then stumbled off my board in tears. I had done it.

The next few days were so exhausting that I was bedridden for most of it. I was still working within this time from my laptop too.

Once the whole week was up, I had surfed maybe 4 times and only caught a handful of waves but it was enough. My aim is still to get to the stage where I can paddle out and catch a wave myself again. I plan to go to Costa Rica and stay there for a month for this sole purpose in the future, one of my life goals!

And then it was back home again. I was exhausted for over 2 weeks after this. I have noticed the similarities between this illness and chronic fatigue. You over do it and are housebound for days afterwards. Well, it IS chronic fatigue too isn't it? When I checked my symptoms in comparison, I literally checked off every box! I even have chronic fatigue listed on my medical card and signed of my doctors too. That’s what people do not understand, this is not just a headache and many people have other chronic illnesses alongside their VM too!



**May 2018 - 3 year anniversary**

I have come so far. Up to this point the one BIGGEST change I did to get better was staying active. Walking everyday has gradually helped to heal my vestibular system to the point that severe migraine attacks do not take me back to square one.

I have still had some relapses but nothing like in the early days where it took two years to heal, now it’s more like 2-3 weeks.

Another MASSIVE thing that changed my life was not focusing on it and being consumed each morning if I could see OK or would it be another dizzy day today.

Dizzy or not, I would just get up and get on with it and I was at a stage where I felt I had more mild days than severe ones and was pretty active on a daily basis.

Gradually I could walk in the park without obsessing over if I could focus on that leaf without it moving etc, could I focus on that car without it jumping, I just ignored it and took my attention off it and enjoyed my walk.

I do believe in some aspects of the book ‘The Secret’ and that you can manifest things you really desire, good or bad depending on your thoughts, so OBSESSING over my symptoms every day did me NO good! It was only when I took on a more positive mindset in my healing journey, that I started to really excel in my healing.

Notice I say ‘healing’ not healed. This will always come back to bite me in the backside when I have overdone things. I have a neurological DISEASE.

But I really found that not focusing on the dizziness resulted in a more positive day for me. The more I focused on how crap I felt, the more I created that reality around me.

It was around this time that I decided to try and go back to full time work again. I managed to give this a trial run as a social media marketing executive in Farringdon. I had an interview and was accepted on the spot much to my surprise! I knew in my heart back then that I would not be able to cope, but I wanted to get back on my feet as soon as possible and live a ‘normal’ life and also thought it would help my relationship too and that I could be more dependent.

So how did my first full time job go? It went something like this.

Day one I was FINE! 8 hours on a computer and travelling, a miracle!

Day 2 I was starting to get tired and by the end of the day I had a migraine and my eyes were really starting to hurt.

Day 3 the dizziness and exhaustion started to kick in, it was so hard to get through the day.

Moving on to day 5, I was so dizzy I was back to not being able to walk straight. I was exhausted and could not see the screen as the words would jump and in meetings I could see their mouths moving but not really take in the information they were giving me, my brain felt numb.

Needless to say I lasted a full 8 working days before I admitted defeat and yes, this hit me hard. I realised I would likely never go back to my career in marketing, 8 hours on a computer, even 4 hours a day was too much.

DON’T feel disheartened as I know of MANY that DID go back to full time work on computers! But we are all different and it wasn’t for me. That part of my life was now dead in the water and this was just something else I was forced to accept.

**July 2018**

Things were not great at home. My partner and I were more like friends and we had a few serious chats about trying to turn things around but it was very obvious his heart was not in it anymore, and I couldn’t blame him.

We obviously were not meant to be. I decided to put my head in the sand here and try and visit family and friends as much as possible to give us space still hoping it might help save our relationship.

I spent the next few months flying to see friends in FInland, France and Bournemouth. I had free accommodation there and could just about manage the flights.

I hoped the space may have made a difference. It was an incredibly hard time as it always is when you realise something is coming to an end and your dreams are dashed before you even get started.

I thought I was coming OUT of the worst of it but it made no difference, my illness had just caused too much damage and after 4.5 years it was nearly over.

The stress and pressure I felt during this time was on another level. I couldn’t sleep, I was anxious all the time, I was depressed and I tried to block it out with drinking or going out with a friend on a Friday drinking and feeling worse over time.

I just KNEW I do not have enough money to survive by myself on my meager 4 hours a day marketing and limited clients dropping away.

Spiritually, I always believed there WAS a god or a higher power but during these years and especially during this time I just felt so much anger towards them. Also, towards my dad that had passed. I cannot count the number of times I have cried out in anger at him to ‘Help me!’ and ‘Have I not been through enough??’.

I was a matter of months away from being single and I had no idea where I was meant to go with barely enough money to keep me afloat for more than a few months rent at best. This hadn’t really hit in the Summer though, it was only in October whilst visiting friends and family in Bournemouth I lost my last big client.

Now it was official. I was not earning enough to make rent even on the cheapest house share in London. I had no family home if this money ran out, nowhere to go. I had the option of my friend's sofa if I ever needed it and she is a busy single mum or 2 kids and I dreaded that scenario. No, I wouldn’t be homeless, but for me I had hit rock bottom.

The government still said I was fit for work as I had failed me ESA. I was COMPLETELY and utterly screwed.

It was around this time and going into Christmas I felt very numb, in shock and then angry with my partner. I had been with him for 5 years, I was leaving this relationship at 38, and this left little time if I ever wanted to start a family, my biological clock was ticking and that added more pressure to me.

It didn’t help the amount of pity I got from my mum at this time about this subject, that I should have left and why did I stay with him for so long, I don't have long left for kids.

At the end of the day, I began to see it in a different light. I was GRATEFUL that he WAS there for so long as I don’t know how I could have made it through the worst without him.

I feel it was more the natural feelings you get when you realise a relationship is ending and you are in shock more to do with my illness but it definitely didn’t help matters.

At the same time, I often used to read these stories in the paper about a husband leaving their wife when she was diagnosed with a serious disease for example and I was always stunned and thought at the time, how cruel, but it is only after living with my partner and realising the effect it had on his life too and that even he started to become depressed, why I no longer place blame.

WHY should you have to stay to look after someone that is sick if you are already not happy in the relationship? So you can both be unhappy?

I decided that once I adjusted to being on my own and making my own living again, I would never put myself in that position again where I was in a relationship where I felt guilty, or unhappy or that they did! I felt better being on my own with no one to answer for or to not have to hide my emotions when I was low, dizzy, bedridden or having a bad day or to put a fake smile on my face to make THEIR life easier just to hold together a relationship that was NOT meant to be.

**Jan 2019 - Moving Out**

The time has come. I have dragged it out as long as possible hoping there may be a turn around. But at the end of the day he wants to move on with his life and I have to move on with mine.

The panic during this time was on another level. I have to be out by a certain date and I still did not have a room. If worse comes to worse I will have to get an AirBNB with my savings.

I go through this time in a state of shock. On one side I feel a lot of resentment and feel it is almost cruel, but it is only now I can see that this relationship was over 9 MONTHS ago and my fear of surviving on my own when I was still too sick to work full time or pay rent and support myself was what was stopping me from moving on. I had kept my head in the sand rather than face reality.

Just 2 weeks before the departure date, I found a room in Putney in a house share with another 5 people. The house was old, falling apart, and grubby yet it went on to be my security blanket for the next 2 years!

We had mice that would run under your bedroom door at night and the ceiling would leak water in the bathroom and was held up with plywood!

On the plus, the area was stunning and I had a HUGE window that would let in the winter sun in the morning, unlike the other flat that was a lot darker by the afternoon.

Make no mistake, to go from living with one person in your own flat to living with 5 others, a mixture of people from different cultures was a big shock. It’s only THEN that you realised the flat before that you saw as a cage to contain you was actually helping you to heal, and then you are grateful for it!

I remember when I finally moved in and said Goodbye to my ex, ( We saw each other a few times after that as friends but realised it was just too soon and too awkward )

I moved all my things in using an Uber and laid on my single bed and just was…… numb. I think the next 4 weeks I was in a state of shock. It was only when I finally moved out that I realised it was over. My house was noisy with people coming and going and the walls were super thin.

I just thought, so this is my life now. I cannot work full time, I have lost all my clients bar 3 and can’t make rent and I have no one except for a trusted friend that would call and check in on me every day! ( You know who you are and I will forever be grateful for your continued friendship ) I lived the next few months in a state of fear and denial. On the plus, in another way, after a month or two and with daily Whatsapp conversations with close friends that kept me sane during this time, I started to ENJOY being on my own.

If I had a bad day I could sleep. If I felt dizzy I could rest and when I was low ( Which was often ) I could cry and not have to hide it anymore and ‘play my part’ that I was OK and I WAS getting better.

I have a neurological disease. WHO and I kidding?

I started to get used to my new surroundings. I was still working part time in the day and constantly trying to source new ways to get an income, but to wake up in that room with the Sun streaming in made me feel more at peace, the act was over.

The noise was out of this world though and I did spend the next year on and off relying on Zopiclone to help as the insomnia started to kick in big time! Washing machines are being turned on at 1 in the morning, people coming back from a late shift at 2 and drying their hair in the bedroom next door. The arguments they would have and fighting! And then downstairs would have arguments too and turn their TV on really loudly very late at night.

I just wanted peace.

So this stage of denial carried on for a month or so……. and then the parties began

**February/ March - The Parties begin**

I know in general there are two types of people when it comes to handling a break up.

The one that takes time to heal, rest, go through their emotions.

And the ones that put their heads in the sand, try to block it out completely and will do ANYTHING to take their mind of it and occupy themselves with things that are less than healthy.

Unfortunately, I was the latter.

The hangovers I had during this time were extreme to say the least. But I was over worrying about my health, I was on a ‘ride or die’ road, going through stages of grief and as much as I tried to really sit with my emotions and take it in, I was just too depressed to take in my new dire circumstances so going out and hitting it hard on the weekends was my escape during this time. I was spiralling to say the least!

I LIVED for the weekends.

I got to know people in my local pub as one was a mutual friend of mine. During this time I would go in every Wednesday night and spend the evening with two close friends putting the worlds to right and laughing….. A lot.

I then started to go to the local bar up the road where you could dance too and made friends there. Within a few weeks I was there every Friday and Saturday and I would dance and dance and dance. Then I would come home and recover for most of the week from the exhaustion of it all and then do it ALL again the next weekend!

I was lucky during this period that I DID work from home so I could wake up late and rest.

I have made friends during this time that I know I will have for life.

Was I still dizzy? Yes, but more episodic so I could have a rough 2 weeks feeling dizzy every day and then be OK. I still had chronic migraines during this time from the intense stress of looking for work and not knowing what job I could actually do, hence going out on the weekends and trying to drink and forget about it all.

Everyone deals with grief differently.

But back then, I was breaking and so depressed again I would live for the weekends. It IS important to note that the months of dancing every weekend made me feel great when it came to my balance and vestibular issues! The alcohol? Not so much!

But I found that being more active and pushing myself and being able to rest for a few days afterwards took my fitness here to another level.

The break up became real when I tentatively created a tinder account….. and saw my ex partner on there. This hit home fast, but in a way it was what I needed. Realistically, our relationship had been over for 9 months, and for a lot of those we had been living together as friends and I HAD to move on.

**Dating**

Oh the joys of tinder. Let’s see what I had going for me. I was fun and honest and genuinely really cared about people.

The downside, I had a chronic illness, I would relapse REGULARLY. I had migraines that made it impossible to get a full time job. I lived in a grubby house with mice and 5 other people. ( I was actually GRATEFUL. I had a house to live in at all! ) but not so easy to explain why at this stage of your life, you have to do that at all.

I felt a sense of shame, that I was a failure, that I would never amount to anything as I would never have my career back again that I spent so many years working hard for.

Another issue was the logistics of dating!

I couldn’t handle bright lights or live music events ( Bands ) the biggest issue was I could not walk far as I would get dizzy and lose my balance.

The last few months I had met a friend daily in a coffee shop to chat and get used to talking again without the exhaustion kicking in.

It HAD started to improve! At first the brain fog was debilitating, and if they talked too quickly or too much and would not let me get a word in, the brain fog would kick in and they had lost me!

I would sort or glaze over with my eyes and not really be present, and then I had to leave straight away as the tiredness would kick in and then the dizziness.

I was getting back on track now, but HOW was I meant to hold a prolonged dialogue for an hour solid and ask questions especially when anxious which as most of us know makes the dizziness worse!

And WHAT would I be looking for? An equal partner? Or would they end up literally being like another carer?

I don’t want to put someone through that again…… I don’t want to put MYSELF through that again….. But my faith in love came through and I was going to give it my best shot!

I was still very aware that I was depressed, that I was NOT healing myself, just avoiding confronting my dire situation and really I should have taken more time to heal, but I pushed it to the back of my mind. I WOULD try again.

**The Dating Life**

Wow it was HARD to go back on the dating scene years later at 38 with a chronic illness to boot! Some male friends openly admitted that they worry about that age as they think the woman will be in a rush to marry and have kids ( Oh Great. ) But AFTER 40 is OK according to them…… great advice there guys.

Add a chronic illness to the mix and it was NOT easy but overall, I met some really nice fun people that to this day we stay in touch with. I found the majority were super understanding and actually asked a lot of questions about the illness and even marvelled how far I had come to get to this point.

This was great for me as it made me look back on my journey and think, wow, I really HAVE achieved so much when it comes to being bedridden a few years back to being in a bar drinking a cocktail!

I was very open about certain things, like talking too much makes me tired and bright lights and standing next to a loud speaker makes me dizzy. That I had to avoid those spinning bar stools like the plague and had to sit close to the ground!

Overall though, it was a fun and positive experience and I don't regret it at all!

**April - Working full time in a school**

Now the real work begins. I spoke to my neuro again and overall my health was really improving and so was my stamina. I also rarely noticed I had any dizziness these days, to be fair it could have been mild but I had lived with it for so long I did not notice it anymore!

I have been waiting to receive a DBS clearance so that I may work with children. I worked with children in the past with the odd bit of nannying and absolutely adored children, I’m also limited as to what jobs I can take due to mainly a marketing background not much else in the last 10 years! I had found an agency that would call me up for shifts in local schools.

Now my DBS had cleared, I was waiting for the calls in the morning to see where I would be heading.

It was NOT easy. I would wake up at 6.30 and get fully dressed and ready to leave the house even if I might not have work that day. I was also very very apprehensive over how I would handle the noise, but at least this position meant I could choose my own hours.

My neurologist agreed that my dizziness had stabilized enough that I rarely felt any at all on a daily basis now and I was in good health overall and had come so far from 5 years ago. As long as I was not on a laptop and I could choose my own hours, nhe felt it might actually improve my vestibular system, the next step up!

Now as always, it was about survival too. I had to pay rent and my savings were nearly gone, things had just got real.

I do wish during this time that I had saved enough over the years to have a complete rest from work. I had worked solidly the whole way through and even the last 2 months I was working part time on computers but it was still not enough to cover my bills.

**The First Day At School**

I remember my first day at a local primary school.

It was so hard! The lights, the noise, the playground, the screaming, the noise in class, the work, I knew it was going to be a big challenge. Luckily, I would only do 2-3 days a week and I was just about managing, but if there is one thing I have learnt about this illness, the odd day or two is OK. It’s the consistency and the need to be at the top of your game for WEEKS in a row that was the challenge.

I had some very, very challenging children. This is nothing new to me as it sort of ran in the family when it came to things like ADHD as children and it was a daily occurence growing up. But with this condition, it became too much.

I agreed to do a 2 weeks stretch in another local school and the teacher there had lost complete control of the class and it was a very tough job. I gave it my all and really enjoyed playing sports with the kids, teaching them how to read and write and working mainly with nursery up to year 4.

But again, the noise, the multitude of tasks, the running around, always on the go, the lights, the movement, I could feel the dizziness start to kick in and I started to take the odd day of two off. I was saved by the Summer holidays and within a week the dizziness started to reside and then my agency agreed that I had been put in some very challenging roles and that they would find me a better position next semester.

I had just enough money to pay rent over the holidays which I had been saving. Things would be very tight but I would just about manage.

**July - The holidays and fading fast**

My agency called and told me they could not always guarantee work and the weeks after the holidays would be very quiet, however there was a full time position in a local school that I really enjoyed working in on some previous shifts and they told me that if it got too much, I could just go back to part time agency work again.

Obviously I was very very nervous, but with bills to pay and weeks to get my strength up again, I decided to give it a go. For now though, time to enjoy the holidays!

**Schools Out For Summer**

The holidays were a calmer time for me. As much fun as dating had been, I had not met anyone I really clicked with, not anyone that I thought could truly understand my condition anyway. I decided that I was better off on my own for a while and really started to accept that I may never find the right person, marry, have children and I was trying to find peace with it.

This illness was just so complicated and I did not want another partner to turn into a carer. It was a depressing thought and I was just about to give up when a friend told me to give it ONE more go.

I had weeks ahead of me or boredom with not much money to entertain myself. I used this time to mainly focus on developing my other side business, my Etsy shop and it was starting to bring small amounts of money in. I was bored and thought, maybe another date wouldn’t be so bad, and so with encouragement from friends, I decided to give it one more go.

I didn’t hold out much hope until I came across a profile of a man that had the kindest smile. I just thought, go for someone kind. We matched and started to chat and then we arranged for a first date. I still was not expecting anything to be honest, but I thought, it’s Summer, you have worked so hard, go out and enjoy it!

**Meeting Markus**

It really was a Cinderella moment and one I will always remember. I met him at a local bar/ restaurant in the middle of a heat wave and I had a green Summer dress on. Parson Green was completely rammed as I made my way to Aragorn house. The nerves started to kick in especially when I got a text saying he had arrived and was out in the garden waiting for me! I entered the building and made my way to the door that led outside, I had to walk down some stairs to get to the garden and it was packed! As I slowly made my way down the stairs, I scanned the scene nervously trying to find him among the throng of people…… and that’s when I locked eyes with him.

He was tall, just over 6ft , Blonde, and very tanned from being away over the Summer. He smiled at me, that lovely kind smile, and I smiled back and I had butterflies in my stomach. I didn’t expect to feel like this!

We were a bit shy at first but it ended up being the most wonderful evening. Afterwards, we continued to date and that was that as the story goes is that! We have now been together for 16 months and It has not been easy! He has to learn about my condition and we have had our fair shares of ups and downs, but overall, you know when you have met the right one for you.

I can’t explain it, there was just something in my gut when I was around him that said to me ‘everything will be OK’. He was very sensitive and caring and considerate and yes, very very kind. We also both had a really really silly sense of humour and also loved to dance and got out socialising. He was a dad of 2 as well which I loved as I had left it very late to have my own children due to this illness and it took the pressure off a little as I was still not sure I could handle a pregnancy or wanted to go through with it all!

But the Summer is nearly over, and now it is time to start my new full time job.

**September - The new school full time**

I was absolutely dreading the start of the year. Not only would I be a TA but I would also be a round the clock carer for a beautiful little girl with cerebral palsy. I had hourly toileting duties to do as well as learning how to use a catheter, which was not made clear when I took the position and made me very nervous until I met the child I would look after. She was beautiful, cheeky and highly intelligent, the best in her class.

I just thought, if she comes in every day determined not to let her illness hold her back, the least I can do is man up and do the same. There was no one else either to look after her at this late stage, only me! The agency had not made it clear to us of her medical needs and I would have to learn quickly. She wore braces and I had to be careful at all times not to let anyone knock into her as she had had a few operations.

All in all, it started off well. The Summer holidays I had been very active, I was hardly dizzy at all anymore unless I was very stressed and I was the fittest I had been in years! I was READY for this!

I became known as her bodyguard as I towered over her and regularly told the older kids off if they rushed past her. I was so protective over her and I lost count of the number of hours we would laugh and play tricks on others in the toilets while we were there, anything to make her laugh when she was having a rough day or would get a little tearful. We had an incredibly close bond and a year later I heard she still asks when Miss Sian will be coming back which breaks my heart.

The first 3 weeks I was managing, but by the time the full 6 weeks were up, I was exhausted! I soon came to realise that the 2 teachers I worked with pretty much left everything to the TA. On top of my duties of teaching 13 children to read and learn numbers in the morning and being a round the clock carer, doing every lunch and break duty, having a table of 8 children that were fussy eaters at lunch time and many other admin jobs, I was COMPLETELY fading.

It was a great school. They were well equipped and even had a swimming pool and the other teachers and I stay in contact to this day.

But as the months wore on, the other teachers could see I was struggling. I found out that the two I worked for never had a TA that lasted for more than a few months as no one wanted to work with them. That and a bitchy environment and snide remarks when I would mention I cannot fit any more in my timetable as I LITERALLY had no space made this situation worse.

My only saving grace was my bond with the other teachers that really felt for me and told me that I was working with the worst two in the school and no one wanted to work with them. It made me feel less guilty that I was so tired and had a chronic illness knowing that even fully FUNCTIONING TA’s couldn’t handle it either!

Just as I hit the 3-4 week mark it finally hit me and I took two days off. As the month went on this was followed by more sporadic days off until it got to the point I was CONSTANTLY dizzy for at least 20 days of the month and then having 13 migraines a month.

I was soooooooo exhausted from the noise, the travel, the early mornings, the screaming, the shouting, the monitoring, being a carer and a TA that I crashed big time. I could not for the life of me get out of bed in the morning. I would struggle to lift my head, dizzy, and it would take everything I had to lift my arm. Yet I STILL would take a day or two off and then go back in once the dizziness reside enough

Then the nosebleeds would start. I would get the WORST nosebleeds I have ever had. I knew I couldn't keep it up and dreaded calling in sick but what I dreaded more was letting down the girl I looked after. She would always ask about me and when I was coming back, but I was spiralling again and fast.

What can you do when you have NO money, NO family that can AFFORD to support you and a government that said I HAD to find a job, no option? There was ONE miracle in the background though. I had started an Etsy shop over the Summer and it was starting to build. I created jewelry, did reiki healing and it was giving me enough money that I hoped one day I could survive on.

I would finish my exhausting shifts at the school and then head home to complete multiple orders, working 2 jobs at once for the next 6 months until my health finally gave up on me completely.

**December/ Jan/ Feb - The Nosebleeds Worsen**

Things have got so bad that I am unable to get up in the morning, but I must. I already failed ESA and I have been told that I HAVE to work by the jobseekers department. I am getting more and more days where I actually physically cannot get up in the morning. The alarm goes and I lift my head, swing my legs over the side and literally drop to the floor, before I realise I can hardly stand up again.

That’s when I started to get the most intense headaches and the nosebleeds started to worsen. I had spoken to my agency numerous times about the amount of work that was expected of me and the catty environment and they kept telling me they would speak to the head teacher as I was doing far too much.

My day was filled every hour doing medical/toileting needs for my child, then teaching my 15 children in the morning, speech therapy with another child, religious studies, breaks and lunches. I also had 8 children that were fussy eaters or had allergies that I would monitor every lunchtime, basic admin, photocopying, afternoon support and teaching, more admin work and the list went on.

I knew for a fact that no other TA had such a demanding role as I was the only one in that school that was both a carer around the clock AND a TA. I wish to this day that I had more support considering the intensity of the role and it was also played down to me. We didn’t know the child's full medical needs until the day before we started the job as the agency had got it wrong. I also realised that they could not find me temp work so last minute after their mistake and I had to pay rent.

I spoke to the head teacher when things came to a head and still nothing was done. It got to the point where the dizziness came back with a vengeance and I had two weeks off feeling dizzy and my sick days went from the odd one off in a 4 week stretch to 2-3 days at a time.

I told my agency my migraines were coming back and I knew I had to stop the role. I knew it was no longer safe for me to work with the children as although I had not had a vertigo attack in a year, and my neuro had cleared me for work as the dizziness had not been there for months now, I was still pushing my body too the extremes and it was also unfair on the child I looked after to be away so much.

I was going to have to leave and go back to part time agency work.

Leaving the girl I had been caring for for the last 6 months was absolutely heartbreaking. We were so close. I was with her every hour of the school day to help with her medical needs and also on lunches and breaks.

I spent a few weeks before I left explaining to her that I would have to leave as Miss Sian gets headaches but it would be OK as I should still be doing the odd shifts in the school. ( I asked my agency to place me here when they needed someone for the day to make the transition easier on her ) but I was never called back in.

I also was responsible for training up the new TA who was absolutely lovely, kind and caring. Not many wanted to take on the role due to the medical aspect of it so I was happy when we found someone.

The one thing I resented was the last week, rather than being able to say bye properly and finish training the new girl up, they didn’t call me in for more shifts as they did not want to pay for two TA’s in the same class.

I was more than heartbroken. I didn’t want her to think I had just left without saying goodbye and I was very upset that I had worked so closely with her for 6 months and I had not finished teaching the new girl about the role.

I think overall, they were a little resentful that I spoke out about the other two teachers and that they were not pulling their weight and were not keen to have me back.

The only plus here was I had worked now in another 9 schools in the local area and was regularly called back and offered other full time positions so I tried not to let this affect me. I knew I was good at what I did and gave it my all.

I was also very proud that the 13 children with learning difficulties I taught in the morning had all gone on to the higher tiers bar one. And one child that struggled to write his name nearly managed to spell the whole thing just before I left.

It hit home though that jobs are just not understanding when it comes to medical conditions and more support is needed for us in the workplace.

PLEASE speak to HR if you are struggling! I know in the UK we have certain rights and chronic migraine is considered a disability and work places have to make changes for us. In my case though, there was no HR to speak too. I knew that if I complained about the teachers my life would be made hell. I was replaceable.

**March - Lockdown - Ice Skating**

I managed to sign up to a new agency with more consistent shifts. I will only be working 3 days a week in local schools. Thanks to my Etsy store I have just enough to pay rent and I will make it OK which is such a relief!

After taking a few weeks to heal, the dizziness resolved itself and my energy started to slowly increase after that. I had started to do the odd shift in a local school and it was manageable but I soon realised even 3 days a week and the travel was pushing it and I would have to take it down to two, just enough to survive and make a living, but nothing to save for later in life.

This was a very hard time for me. I felt very low and depressed that my health had declined so rapidly, so quickly especially after reaching my peak fitness level since the illness took hold! I truly believed that after 4 years on the mend that I was well enough for full time work but this was simply not the case.

It dawned on me that although I thought I was making major strides over the last 4 years and to an extent, that is true, I still had worked from home the whole time and woke up late for the majority of it and was in the safety of my room.

I was not prepared for the early morning, the daily tube rides, the buses, the long daily commutes across London, the noise, the lights, the shouting, the screaming, the intensity of the role I had chosen.

It really dawned on me then that it is likely I will never be able to return to full time work. My career was truly over. I could not go back and study, I had already given up two courses and a degree as I could simply not do the work load or make the daily commutes so re training in something was just a no no.

I needed a job with no bright office lights, not much noise, no screen time, no standing up for prolonged periods, no stress lol, no long commutes, not much talking…… can you imagine???

So working in schools was the best I was going to get as I had experience with children previously.

I just want to say here I am one of the lucky ones, in the fact that I DID manage to turn my Esty shop into a success where it surpassed my full time TA salary. I know so many more that HAVE to push through in jobs and go through SO many complications with their jobs trying to fire them as they take too much time off sick, HR interfering, staff members looking down at you as you are sick all the time.

Yes I HAVE been there too, but with my Etsy shop there was at least SOME light at the end of the tunnel. I would survive.

So just as I had started to do my new shifts, 2 weeks into the semester, COVID hit. The schools closed down and I was off work for the foreseeable future. Luckily for me, I now was able to just about survive through my etsy shop.

**May - Rollerblading**

When lockdown hit, it was tough. I was in a house share and had a room but no living room and being in all the time actually started to send me spiralling back to relapsing again.

I was very lucky at this time that the weather was amazing and I started ice skating once a week and then roller blading when the rinks closed.

I was very on and off health wise during this time. Stress is my number one trigger and my migraines increased a lot. Then I started to overdo it with the rollerblading.

One week I skated three times and had a three week relapse! I need to add that when I skated I could only skate each time for 15 minutes tops. If you want to know about balance here, my balance funnily enough was pretty good! But AFTER 15 minutes the jelly legs would kick in, then the brain fog, then the dizziness, then the couple of days in bed and on the down low as I was soooo tired!

I knew from experience though to try and stay active or I would start to go back on myself. In the end, I settled for 1-2 miles a day of walking and again, I started to get better.

**February 2021.**

We are currently back in lockdown again, our third one. I still try and walk a mile a day if not more. It had not been easy on any of us. It will probably be well over a year until I see my mum again, currently my partner is in another country for another 2 months so I am back in my room writing this.

My migraines have increased to 15 a month last month, but trying to keep the stress down, walking every day and also being able to work my own hours has really helped me to manage it better. I cut out coffee which was never a trigger before but since I have been migraine free for 2 weeks now!

I know mental health has definitely come to the forefront for the entire NATION during this time. You do not feel so alone with depression if you know others are struggling too and I have noticed it’s not a dirty word anymore and more people are choosing to open up and be vulnerable.

Although it has been a hard time, I have a loving partner that I know has my back and I feel we will make it through the current hardships. I also currently have a roof over my head, friends I can speak to if I need too. I am NOT dizzy consistently nearly every day now. I also know my biggest triggers and what to avoid. I have learnt the most important thing too which is to say ‘NO’. I cannot do that today, I am tired.

I know as harsh as it sounds, that cutting people out of my life that put an added strain on me is necessary. I can no longer talk daily on the phone and try to be a ‘good friend’ and offer solutions to other people's drama. I need my own space and I need to conserve my energy. I have a chronic illness, they don’t.

I have also learnt that as much as London has been a blessing in helping me get back on my feet with its vestibular overload, I actually would like more peace now, and more quiet. I would like to go to sleep and not hear the neighbours T.V next door, I would like to hear complete silence.

I look forward to more trips away once this is over. I work from my laptop so this allows me to travel now.

More importantly I know I am a survivor and my dad would be proud. I know that if I lost everything tomorrow, I COULD rebuild with grit and determination. And when I get depressed again, I know I have friends to talk too and help lines if needed.

Sometimes I feel life is so hard, but considering where I have come from, I truly have hope for the future.

I found that the method of learning about the migraine threshold REALLY helped me! This means that one day you may be able to have one of your triggers such as chocolate, but the next day you can’t. And that’s because you have a certain threshold and if you go above that you will have an attack.

So if I have a coffee, my trigger, it’s not likely to push me over the edge. But if I have a coffee, no sleep AND a lot of stress then I am likely to surpass my migraine threshold.

As for medication, after my recent 15 migraines in a month, I decided to go back to my neuro and we are either looking into Botox injections or Aimovig, the first migraine injection of its kind once it has been cleared for the UK.

I will carry on taking Sumatriptan until then as my emergency migraine med and I personally do not want to take preventatives again as I was just so super sensitive to them and I’ve worked my way through the list by now!

**The Future - Children**

When all this started I was at the age where I should have been considering if I wanted a family or not. I absolutely ADORE children, but I was not ready at 34 to decide if I was ready to be a mother or not mainly down to this was a new relationship and then BAM……. The illness hit me under a year into dating and consumed my life ever since. I’m now 39 and I’m aware that my chances are slipping away. I have considered fostering if it came down to it.

I am also aware that there is a 50% chance that if I have a child vestibular migraines could be passed down to them. I have strong migraine genes on both sides of the family - members being on preventative meds.

My biggest fear is what happens if they get to 18, and then it kicks in and they want to travel, go to Uni? What if they have their whole life ahead of them and then this completely wipes them out? And it's’ something I gave them? I hope by then that there will be adequate support and good medication that will help compared to what we have now where we rely on anti depressants etc as there is NO set drug for migraines until recently, the migraine injection Aimovig.

My BIGGEST fear has to be relapsing so badly that I can not look after a baby. I have heard many feel great when they are in pregnancy and often feel better but after is when it hits them.

I honestly don’t know how I would even pick a baby up with dizziness and vertigo, the crying, the lack of sleep, the feeding. Would it be enough?

I am VERY grateful to all the support when I asked this question in our Vestibular Migraine Support Facebook group. Such lovely words of support from mums with grown kids and also new mums and mums to be! It gives me hope that just as I got through this, I can get through motherhood too and the pregnancy.

Right now I am just biding my time a little longer….. My mum had my brother at 38 so this gives me a little more hope that I too could be on the same trajectory as her but I’ll have to see. It’s something I often overthink and stress out about. Right now I am not trying to get pregnant, wow I am still trying to build a life again! I want roots and stability. I do know ONE thing. I will forever be grateful that my mum has VM too. It actually made us a lot closer. We talk on the phone every week and she is the ONE person that understands what I’m going through.

It gives me hope that if I do have a child, then they will have the same support, understanding and bond that my mum and I have.

**End Note**

Accepting that this is now your life and there is nothing you can do about it is not true but you literally have to get up each morning and fight to walk that 100 metres to the shop, even if you can’t see very well or feel you will fall over as with time, I managed to improve massively by testing myself each day.

It’s very easy to become housebound with this condition, but living and working in London I had no choice but to go out everyday to busy supermarkets, catch busy tubes to doctors appointments and manage busy high streets packed full of people.

I am certain that I am where I am today because rather than avoid my triggers I confronted them. Always remember it CAN be extremely hard to find compassion from loved ones as we look fine! I’ve often thought people would be more accepting if I had a physical symptom or illness.

Be aware that there are literally THOUSANDS of people suffering from this, most of them undiagnosed and it’s important you reach out to others in relevant support groups such as Facebook groups for vestibular conditions. I found that talking to others that could understand my symptoms and have compassion for me whilst others found it hard kept me sane.

There is NO shame in asking for help if you need it! I would not be here writing this book to support others if I had NOT reached out! Please remember that!

I finally have some hope for the future and I truly believe that yes, we may need to live a calmer life and slow down, but there are still beautiful things to be enjoyed in this world and I am very grateful I am here to experience them.

**Below are Posts For Inspiration taken from my website or migraine posts.**

**A Blog Post From My Website**

‘It all started around 6 months ago.

A short walk to the park to meet a friend for lunch suddenly sent my head in a spin.

Putting it down to low blood sugar I went back to work only to have a near fainting dizzy spell 2 days later on the train. I stumbled off and did everything I could to stop the nausea and the spinning but the cold sweats sent me home to bed.

The next 10 days were a mixture of nausea and unable to focus on anything at all without it moving. My legs felt like they would disappear into a marshmallow floor. I finally hauled myself over to the doctors to be diagnosed with viral Labyrinthitis. What??

6 of us had been struck down with this illness in the office, very odd, one has been off work for at least 3 months last year and STILL has the effects.

I powered through for months and was lucky enough to be able to work from home and only go in a few days a week AND only work 5 hours a day. But even that got too much. The words would jump out at the screen and flash. Even now Im having real difficulties in focusing and feeling a bit sick so this will be a short post.

I am now currently signed off for a month after a horrific episode where I was bedridden for 5 days, barely able to move my arms. Now when I turn my head it feels like it takes a few minutes for my eyes to catch up. I have found that the anxiety worsens the condition greatly and as a born worrier it's been a nightmare.

Massaging the back of my neck helps slightly as I believe it aids the restricted blood flow to my brain and makes me feel slightly more alert but currently I cannot walk for more than a few minutes and as for an 8 hour day on a laptop? No chance.

I found it greatly added to the dizziness, migraines and headaches.

Also I find it hard to remember things, even to string a sentence together.

It’s really frustrating.

**Blog Post Below**

What a name….. for over a year I suffered from constant dizziness, exhaustion and anxiety to name but a few symptoms. I was diagnosed with labyrinthitis, then FINALLY 2 weeks ago I saw a neurologist who told me it was actually migraines. Janet Jackson has recently pushed this condition to the forefront as she suffers from it too and had to cancel her concerts in the US.

Here’s what I have learnt.

* Not everyone has actually headaches, sometimes you will feel extremely dizzy and exhausted and not even realise you are going through an attack.
* It tends to be more prevalent in women – My mum suffers from constant dizziness due to this too as well as my half sisters interestingly enough.
* You look FINE! The harder part is you look fine, it’s not like you have anything to show for it, like a cast on a broken arm so it’s extremely hard to tell friends than your having a rough day and are more limited to what you can do.
* Overdoing it will make it worse – True I find walking a lot and pushing myself to go out helps me feel less like a recluse but the next day I’ll expect to spend a good few hours in bed. And that’s not even a night out drinking!
* You realise who your real friends are – I have literally stepped back from a few, our lifestyles are completely out of sync now and I just would rather avoid the drama and stress.
* Mind over matter – Acting as normal as possible and carrying on through the dizzy days helps, Who wants to moan day in and day out they feel like crap? It WON'T change anything other than make you feel worse.
* Thoughts are things – I really believe that what you think about the most you will draw that to you. There have been weeks when I have thought positively about my situation, that I’m healing and I felt better. When I have a relapse and feel worse, if I worry about it and feel sorry for myself it takes longer to recover!
* Changing your lifestyle is a MUST! I used to go out every weekend and really party hard so to speak lol, even though I’m 35 I wasn’t slowing down in the slightest. Age is just a number after all. But now I can manage a few hours before the tiredness kicks in and I know when to stop.

**A Blog Post From My Website**

Considering I have been diagnosed with Labyrinthitus for well over a year which in fact, turned out to be vestibular migraines, sometimes it really is almost impossible to differentiate between the two.

16 months ago, after an extremely stressful period at work, I caught a virus which doctors believed was Labyrinthitus. It was only when everyone returned to work after 2 weeks and 3 months later I was STILL housebound with chronic dizziness, I really started to question it.

The common symptoms for BOTH conditions can be exactly the same;

Tinnitus

Exhaustion

Constant Dizziness

Pins & Needles

Anxiety

Weak Legs

Insomnia

In fact, I’m certain a lot of people have been misdiagnosed with one or the other and with over 350 symptoms that can cause dizziness, you can expect a long road to get to your diagnosis. ESPECIALLY when the migraines are mostly silent like mine.

So how WAS I diagnosed? So I had;

Vestibular Testing

Ear tests

MRI scan

Blood Tests

3 x Eye Tests

Eye Hospital Check Up

EVERYTHING CAME UP NORMAL!

In the end, it took over 13 months to finally get to see a specialist called Dr Barry Seemungal based in Charing Cross Hospital in London. He is a well known neurologist and his diagnosis took under 15 minutes once I explained my symptoms.

He told me that because of my family history of migraines and my mum also being a sufferer it is most likely vestibular migraines. I then also saw another 2 migraine specialists that also told me it’s vestibular migraines because I have a history of them in the family.

They believed the stress at work, flu and possibly an old whiplash injury – apparently whiplash injuries are a common cause for vestibular migraines, a large number of patients they treated previously had a head or neck injury – made me very susceptible to this kind of migraine.

The thing is, once you’ve be labelled with a condition, the next doctor you see is going to treat you for that condition. In my case I saw 8 doctors and they all treated me for Labyrinthitis because that’s what the previous doctor said I had!

Even when I protested about the meds not working or really bad side effects, and is it possibly Vestibular migraines as migraines run in the family, it took me to see a specialist to finally have it confirmed.

My eyes most of the time! I ended up getting fillers just so I wouldn’t look ill all the time and I got tired of people asking me are you ok? Even on a good day!

IT WAS MY FAMILY HISTORY THAT FINALLY GAVE ME MY DIAGNOSIS

I am now taking a blood pressure tablet called Candesartan and although it’s only 3 weeks in, the dizziness has lessened dramatically and the headaches too.

I’ve learnt that anything can happen with this condition. You can be planning a trip to Paris on a short break after a great 2 months, and then BAM, new conditions hit you forcing you to be housebound for weeks until you build your strength up.

Each time this happens, you lose your confidence in your own abilities and it makes it harder and harder to get that tube train, or catch that bus as the anxiety that something could happen again is always there.

This is what I’m doing to cope;

When I feel low I make an effort to go out for a coffee, even if it’s only a 2 minute walk

I’ve started to look into counselling so that I can deal with living with this condition

I put myself in at LEAST 1 uncomfortable situation a week, a tube ride or a packed shop

When I need to I listen to my body and rest – Even if that’s 5 days solid in my house

I don’t make myself feel guilty anymore, I am coming to accept it and not fight it, only then can I start to understand this condition and treat it.

Still a long way to go but currently more hopeful, I may never get back to working full time and having the career I always wanted but I’m booking my first long haul holiday in over 16 months to Cuba next year and starting up the gym.

**🙏 Job Losses 🙏**

Migraine is a neurological disease. There IS no cure.

On the plus, where Migraines used to be treated with things like Anti-Depressants, we are starting to see more medication created specifically for migraine.

I worked very hard for 10 years to be a travel and content writer. When this hit I had to give up my career and yet I STILL Fought against it and after 3 years and the dizziness clearing up, I went back to a marketing role in the hopes to continue my dream.

Within days, I was back to being bedridden. I tried ONCE more and again, I was so dizzy after just 4 hours a day on a PC I realised I had to give this dream up. I have slowed my life down completely and I now work from home and am far happier.

My friend, however, worked full time in a high position in a bank. After just a year, they are back to this position and I know another 4 that all work full time again in offices on computers.

The healing journey is different for everyone. I LOVE what [Heather R Davies](https://www.facebook.com/groups/1259447570808227/user/100003140306641/?__cft__%5B0%5D=AZWKonwHG5SfMQAPR72yox6VxLRLwbe6B3Miow-D5kXQRMjHfQJeSBdmOhnrp3xZOko75yrLgoo0i0p6l-N7hF0-KraRGlo00WSMOgsyRpHBPqANE6T2zmUCltCKKhiI5VfzcxCQhAr_21jnxbA0zksVgd5XZF6Hnun2T0FUCeV1ZQWxXPtvjwurrHwnPFAFqEE&__tn__=-%5DK-R) said about 'Changing the dream' and taking all that pressure off yourself if you CAN'T go back to where you were in your career and to change the plan.

I still get migraines, 11 this month to be exact after issues with noisy neighbours BUT I am rarely dizzy anymore and I can walk a few miles a day and lift light weights and lead a fairly normal life most of the time.

I know now I will never have that 'dream' career I always wanted but I have made peace with that over the last 4 years and I am just grateful to not have 24/7 dizziness and to be able to go for a long walk! More importantly to STILL manage to make a living!

**❤ Dating ❤**

Someone mentioned how do you date with this? So I thought I would share my experience.

My last relationship of 5 years broke down due to my illness. I was reluctant to date again as I knew I had to answer so many questions, about why I gave up my career, why I shared a house at the time with 5 other people, why I only worked part-time, why I can't go and see that band, why I can't stand up for more than 15 minutes without swaying, why I can't go shopping as I will get dizzy if I walk around too long..... you name it.....

I actually went on a number of dates and I found that most people are really understanding and to be honest, it did not stop me from trying to find love.

7 months into dating I met my current partner and 16 months later we are still together and moving in together in the Summer.

I DO know that in the early days when I was bedridden and couldn't leave the house, of COURSE I couldn't date lol, but as I gradually healed, stayed active, and built up my resilience for bing in a coffee shop, a bar, a walk in the local park, it gave me more confidence and I'm so pleased I kept on trying!

**⭐ Instagram post @viking\_wanderer ⭐**

Vestibular migraines before and after..... Miracle cure? There is NO cure but I'm back to 95%!

I also got under-eye fillers to stop the 'You look sick /tired' comments. It made a MASSIVE difference to me mentally not to be told I looked sick and even on bad days to look in the mirror and look ok spurred me on more. 🤔

But it gives you an idea of where I was 4 years ago.

⭐ I couldn't walk properly for 2 years, the ground felt like it dropped beneath my feet and at my worst, I had to be held up

⭐ I couldn't see properly for 2 years, everything moved and nothing was in focus properly

⭐ The chronic dizziness and imbalance was there for 3 years

⭐ At my worst I was bedridden for weeks, I couldn't even wash my hair and had to crawl to the bathroom

⭐ It felt like that feeling when your head spins after drinking too much.... Everyday 24/7 for years!

⭐ My eyelids would really swell up and my eyes would go really dark

⭐ I used to walk into things, walls, people. I couldn't do the most basic things like cross a road by myself.

⭐ I had insomnia, depression, anxiety, exhaustion and at my worst I was suicidal.

AND NOW?

❄️ I can walk for over an hour before I start to feel a little dizzy

❄️ I have not had a migraine in 7 weeks

❄️ I have just started figure skating!

❄️ I am working part time with children.... It's noisy! And I work 2 days a week from home.

❄️ I can fly, travel and go clubbing and I managed to go paddle boarding and surf again!

THERE IS HOPE!

My top tips are to....

🍾 Stay active! Walk daily if possible!

🍾 Remove stressful people from your life

🍾 Do not just rely on meds, when you're vestibular system hard been destroyed you're like a toddler learning to walk again....

🍾 Have massage, reiki, acupuncture, try alternative therapies.

🍾 Learn to say NO!

🍾 Find a good support group, you'll find your REAL friends through this illness... And it's depressing and lonely

If you are feeling depressed or that you can't go on another day with this, please join our Facebook group vestibular migraine support or TELL someone! .

THERE IS HOPE!

**💜 Relationships & VM 💜**

A bit more personal but I know relationships are a big struggle and also a lot have ended and people wondered if they would ever find love again.

I broke up with my ex at my lowest when I had depression and not enough money to last on my own more than three months.

It was such a shock as we had been together for five years and lived together and I thought he was my forever partner. The illness just became too much for us to overcome

A year later, I had found work, a new place and lot's of new friends ( Sharing a house with 5 others forces you to do that!) although it was so tough going! I dated but it was tricky and I resigned myself to never finding someone that would stick by me and was starting to accept I'd RATHER be on my own than have to have guilt about my illness or LET them guilt me!

I went for a date not expecting too much to be honest and there he was. It's been 14 months together now. He tries to understand my illness but when he can't he'll give me a big hug, tell me he loves me and it will all be ok.

I know he's got my back.

I truly believe there's someone out there that will love us just the way we are. So don't be put off from dating etc or looking for love again.

X x x

**❤ Feeling Guilty ❤**

I don't know about you, but I have felt so guilty for my condition for the last 5 years, and then boom! In the last 8 months, something changed in me and I thought NO! NO more!

It's incredibly hard when the people you love the MOST do not understand how sick you really are or feel you are being 'dramatic' or acting up.

A chronic illness is there for life and needs to be managed carefully, not just a day like most of them seem to think....... 'Oh, do you STILL have that?' etc.

I'm a people pleaser and a massive worrier and I used to spend AGES worried about letting people down and knowing that they were annoyed that I couldn't do this, or that etc. From close family members, my ex's parents, even friends I had for over 20 years!

But NO more! Now I tell them VERY firmly NO! I can't make it today, I feel like crap and I don't even wait for their response or give a crap about what they think and the crazy thing is, since I have put down stronger boundaries with some of these people they actually respect me more!

So yes, from someone who is a people pleaser, constantly anxious, put yourself and your needs first for 2021 and put down stronger boundaries if you need to. Learning to say no was the best thing I learnt in the last 8 months.

I'm still learning to say no to chocolate and almond croissants but that's another story. ( Damn my local bakery....... )

**💜 DEALING WITH GUILT 💜**

Probably the HARDEST thing I had to deal with in this illness was feeling a burden on friends and loved ones.

I also had to deal with feelings of shame after I lost my job and had to borrow money my elderly mother didn't have.

I was 35, I should have been supporting her, not the other way around.

I often lied to friends & loved ones that I was feeling a little 'better today' just to make life easier as after months of being sick, I could tell my illness was wearing thin on them.

Not to mention a stressed out partner back then on breaking point after two years of being more like a carer.

I want to tell you that we did not CHOOSE to get sick, it was out of our hands and I refuse to punish myself any longer for it or feel guilty.

I created stronger boundaries and put my foot down and say 'No, I am not well enough to do that today' and they can like it or lump it. I no longer care.

I also stopped seeing people that could not understand it and just drained me as I should not have to explain a million times a day what my limits are, enough.

The people that truly love you and are meant to be with you WILL stay in your life and if not, I found new ones came in unexpectedly.

So no, literally guilt can do one!

##### ❤️ **STAYING ACTIVE ❤️**

Just a heads up guys but I am five years in and I was pretty much functioning at a normal level, but since I am home a lot now due to lockdowns etc I have realised I am gradually getting worse as time goes by.

Usually, living in London, I am on tubes, escalators, packed streets, walking a lot and skating and now apart from the odd walk I rarely get much exercise.

I realised all the trains, travel, people and crossing roads is vestibular therapy in itself!! I am now going back to get VRT through my doctor.

I realised this will always be a work in process and just wanted you to know that for me, staying so active really helped me to function at a high level and also got me back on my feet the quickest!

**❤️ EXHAUSTION ❤️**

I still get this now if I have overdone it but in the early days, just trying to wash my hair took EVERYTHING I had! Also, I have lost count of the number of times where I am so exhausted I am bedridden and my arm feels like a led weight and It takes EVERYTHING I have to speak.

Apparently, this is normal with a severe vestibular disorder until you start to adjust and heal and it can take many many months! I think that's why Vestibular therapy puts people off due to the exhaustion and dizziness.

To let you know, five months into this illness I gave up vestibular therapy as it made me too sick and dizzy and tired but I went BACK to it 5 months later and this time, as I was slowly healing, it got me back on my feet and recently I even went windsurfing.

Over the years I can now dance and do things that seemed impossible back then but I STILL need to be careful not to get too excited and overdo it or I am in bed again.

**💜 RELAPSES 💜**

In the first few years I was constantly having horrendous relapses to the point I thought I would go back to being bedridden for weeks again.

My neurologist said something to me I've never forgotten though.

He said monitor the time BETWEEN relapses to see if you are improving rather than the relapse itself and I DID notice over the years it became months between them rather than 3 days!

I now avoid these triggers below.

💜 Stress

💜 Over doing exercise

💜 Lack of sleep

💜 Anxiety - Working on it with meditation!

💜 Too much computer time

💜 Loud noises and bright lights for a prolonged period

IF I get three to four triggers, it's enough to give me a massive relapse again, the last one being three weeks.

So after five years, YES, I am so much better, less dizzy everyday but that's because I had no choice to try and manage it better and it's STILL a work in progress.

I also work from home now which to me was the biggest game changer.

VRT - It's important to mention that many give up VRT as in the early days they feel so dizzy they want to avoid any exercises that made them dizzier!

I remember walking out of my VRT class as I was so dizzy BUT 4 months later, once my vestibular system had calmed down a lot more, I returned to it AND walking every day for at least 15-20 minutes and it got me back to 95%.

Most days I have no dizziness at all.

So if it didn't work the first time, it is worth going back and exploring it. The exercises are MEANT to make you feel dizzy as it means your body will adjust faster to the movements and over time you will feel LESS dizzy.

We would time my exercise over a month so after each exercise, the practitioners would get out a stopwatch and time how long I felt dizzy for and after 6 weeks of this the time dropped right down so I know for me it worked 100%!

##### ❤️ **DOCTORS APPOINTMENTS ❤️**

I have spoken to many who are upset as their doctor thinks they just have anxiety or tells them it's all in their head.

There are over 300 conditions that can cause dizziness so now you may understand what your doctor is up against.

If your doctor is NOT helpful, ask to see another one in the surgery or change completely if you have to. You have NO loyalty to this person, no matter how many years they have treated you in the past.

You put your HEALTH and RECOVERY first........ end of.

Lastly, I equipped myself with enough information on my condition that I could go in and educate HER and she was fine as she had NEVER come across someone with VM before. She even googled it!

So if they say it is just anxiety, it's helpful if you can meet them halfway and know your stuff too.

This condition is stressful enough without a supposed health expert telling us it is all in our heads!!!

IMPORTANT - You hardly EVER hear of people making a full recovery.

That's because the people that DO have been through SO much with this illness, they want to move forward and NOT back.

Think about it, why on EARTH would you want to come back to this group and relive every incredibly painful experience you ever had?

Would you not rather go on living your life to the full and appreciating every minute you have and put an incredibly traumatic experience behind you?

That's why you don't hear of many success stories but they do exist! I know plenty that have gone back to their full-time jobs etc so have hope!!!