

NMO - MY EXPERIENCE, MY WAY 2019

A LITTLE ABOUT MYSELF – WHEN I WAS FIRST DIAGNOSED – SYMPTOMS, THE FEELINGS I HAD, HOW I REACTED.....

My name is James and in April 2017, as a healthy athletic 23 year old man, I had my first seizure and when I came round could not feel anything from the waist down. My symptoms manifested as being unable to pass urine, unable to move my legs, constipation, headaches and so called “MS Band” where I felt tightness around my chest. My diagnosis initially was ADEM and I felt quite positive, embracing physiotherapy and exercise determined to get back to where I had been before. However in November 2017 when my steroids stopped I became sick again; double vision, vomiting and fainting. This time I was diagnosed with NMO with MOG anti bodies. I felt depressed, uncertain what the future held. However again I threw myself back into exercise and also started seeing a therapist. This helped me come to terms with everything that had happened and changed putting me on the right path.

THINGS I WOULD HAVE DONE THE SAME/ DIFFERENT IN THE EARLY DAYS

In the early days I was hard on myself. I wet the bed and would start to cry and get angry, whereas really I should have been kind and realised it was not my fault and not that big a deal in the scheme of things. I also did not really know what to avoid – all you can eat Chinese two weeks into recovery was a TERRIBLE idea and resulted in some quite severe gastro distress...

One thing I did right was embracing physio – do it. Whatever you can. Yes it's hard, yes it can be demoralising; but if you want any progress to be made that is what you need to do.

WHAT ADVICE I WOULD GIVE MYSELF IN THE EARLY DAYS.....

Take things slowly, do not turn down any help that is offered, and lean on those around you. Also do the things that make you happy.

THE EFFECT ON FAMILY/FRIENDS

I think for my family it was just incredibly hard. My dad got both very angry and upset at different times, but when I was well became very positive, maybe too positive. For my mum, she internalised lots of the feelings she had, but sought therapy eventually which helped her. She still says she has to go to the toilet when I call her out of the blue as she assumes a disaster of some sort!

For my friends, I think they were really worried, but I don't know how it affected them really. They all stood by me; but now I think I am not as good at staying in touch, which might upset them. It's hard to say and something I want to do is make more effort to stay in touch with them all.

IMPACT ON MY WORK

I was ill for the first time in a job that I did not really like. They were fine; but they did not put the extra work in to welcome me back. However I changed jobs and now work for an amazing charity (CLIC Sargent) who really supported me. I had a month of full pay sick leave (I had only worked there for 2 months at that time) and all that time they reassured me that I would have a place when I came back. I have now been there for 18 months and have since been promoted. I love what I do and I am very lucky that CLIC Sargent totally support me and make working easy. They know I have some slightly different needs to other people and they work with me to ensure that work is as easy as it can be for me.

IMPACT ON MY SOCIAL LIFE/LEISURE

The biggest thing is my energy. I put a lot of myself in to work and into exercise – things I love but that means I don't have as much

left for socialising as I used to. Also I am a little more conscious of my health and needing to sleep. A lot of my friends are into drinking and staying out late (I loved that to!) but now I have to measure myself and be sure I have enough energy to do the things I need to do. However on the whole my friends are amazing and support me, making time to see me and do things that are more in line with what I can do.

IMPACT ON MY RELATIONSHIPS

My relationships with my family are stronger. Me and my brother were not close, but now we really are.

For me I love my girlfriend Laura, but I think she is better placed to talk about that.

Laura: For me there isn't really an impact it might sound silly to say but James makes it seem fine. He just gets on with it every day and sometimes I can even forget he has it. In the beginning when he was first diagnosed it was a scary time. We didn't know what it was and your brain goes to the darkest places. When we realised what it was it was a relief in a way I knew it wasn't going to be easy and that it wasn't a quick fix for James, but I could help him get through it. It was really hard for James at first he had been through so much not just from this illness but others previously, he did get quite depressed. There was a time when he thought it was better for me to not be with him, I made him realise that there was no better place for me. That was hard but only because it's the worst feeling in the world when the person you love most feels that sad its hard to watch. He got himself out of it though by going to therapy he did it all by himself and I have never been so proud, therapy was the best thing for him and I would advise anyone going through a hard time to do it. After time he managed to feel like his old self again and our relationship has gone from strength to strength, we live together now and our future looks pretty darn great.

TOP TIPS FOR KEEPING ACTIVE AND HEALTHY

I am a very active person anyway but when I was recovering the weather was good and I started gardening. This was a great start to gentle exercise which gets the muscles working. Also it's good for the mental health to have a project you are building – no matter how small.

THINGS I HAVE LEARNT ALONG THE WAY

Neurological diseases suck. People with hidden disabilities have a rough ride – don't be afraid to just go in to a coffee shop and use a toilet if you need to! (Also get a "I can't wait card" it will give you the confidence to go right ahead and do it.)

HOW I COPE ON A DAILY BASIS

I have reached a point where things are good – this isn't a struggle any more. But when it was I got help (therapy, family, time off work) all of that helped. Also look for a chance to find a hobby, exercise for me but it can be anything! Also have a purpose, I am lucky that my job gives me a lot of fulfilment but if you aren't finding that then look for a chance to volunteer as that could be a real path to fulfilling change!

WHAT I WOULD LIKE TO SAY AS A WAY OF KEEPING POSITIVE AND GETTING THE MOST OUT OF LIFE.....

Put the things you love and the people you love at the centre of your life. Then you cannot go too far wrong. There is no magic formula, but no matter what level of capability you have there is a level of happiness you can find but you will have to search for it.