

NMO - MY EXPERIENCE, MY WAY 2019

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

I was initially diagnosed with MS in 1996 when I was 30. Although I had had optic neuritis as a first symptom a few years earlier, tests for NMO were not routinely carried out at that time. After 4 years of treatment with Beta Interferon and a lot of nasty relapses, it was thought that maybe I had NMO. I was swapped to treatment for immuno-suppression, and things turned around dramatically.

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

After my first optic neuritis attack, I had no idea of what the future could hold. Maybe if I had been advised to do some travelling, I would have taken up that advice.

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

However your illness progresses, there are some things that can never be taken away from you. These are the experiences that you have had in life – holidays, theatre trips, exhibitions, music – whatever you enjoy. Always take the time and the opportunity to have as many experiences as you can. Use your energy wisely in order to enable you to do this.

THE EFFECT ON FAMILY/FRIENDS

My family and friends were amazing. They spent hours visiting me during relapses, and were incredibly supportive. Still now, I have many trips away with friends and they are so accommodating about me having to choose places that are wheelchair accessible. If it was

the other way around, I am sure that I would be irritated, but they never show it!

IMPACT ON MY WORK

I carried on working for as long as I could, but eventually I had to retire on ill-health grounds. There is an issue that people feel defined by their work, but this doesn't have to be the case. Also, you can adapt and use your skills in different ways that are fulfilling for you and helpful to others.

IMPACT ON MY SOCIAL LIFE/LEISURE

As a wheelchair user, it can be exhausting and a bit depressing trawling through access details and finding suitable places to go, but it is always worth it, and with a bit of research you can make sure that there are no disasters! It is so important to keep up with your friends and to get out and about.

IMPACT ON MY RELATIONSHIPS

My long-term partner and I separated a few years after my diagnosis, for reasons not directly related to the illness. We are still friends.

I was on my own for a few years, which was a very empowering time. I learned about my own strength, and the incredible support of family and friends.

Since then I have been in a relationship for 10 years with someone who is fully aware of the illness, but who sees me for who I am. Apart from a few hospital visits together, NMO has very little effect on our relationship.

TOP TIPS FOR KEEPING ACTIVE AND HEALTHY

Join an exercise group – no one does exercises on their own at home!

Eat healthily, but don't be too strict. Enjoy your food, and eating out.

Take vitamin D to help with fatigue

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

Make sure that you get your home adapted to suit your needs. Don't struggle.

Don't accept second best in anything.

Always remember that there are people who are much worse off than you. I found this out on my stays in hospital, but think globally as well.

Amongst the people that you meet, it is not always obvious, but everybody has something to worry about.

Don't compare yourself to other people who on the face of things seem to have a better life than you – no one has a perfect life.

There are lots of things to be grateful for – focus on those.

Notice your enjoyment of the small things – being in the garden, watching your favourite soap opera, cooking some food.