

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 diagnosed with NMO illness in February 2011. I was in pain from waist down and could not feel my legs. I had pin and needles in both my legs and couldn't walk. The pain was so severe in my legs and my nerves would hurt so much. I was in total shock that left me worried and I didn't understand what was happening to me. One min I walking and next was bed bound. Why me? I stopped believing in God. I cried to my family and felt depressed and felt I will never walk again. They did so many tests and the outcome was my spinal cord had inflammation and damage to the myelin sheath. Initially I was diagnosed with Transverse Myelitis which was later changed to NMO. I was told and there was no cure for it. They started me on 60mg Prednisolone and some medication for nerve pain.

Things I would have done the same/ different in the early days.....

Accepting my illness is very important and the way forward. Have to have patience there is no quick fix. My hospital wasn't aware there are two NMO centres which specialises in NMO and provides advisory service. I would have sought early referral to Oxford JR hospital. NMO centre needs create lot of awareness to other hospitals in the country. Don't have negative thoughts, about worst scenario.

What advice I would give myself in the early days.....

To think positive. Try not to reflect on what has happened and why me? Set small goals and how I can achieve them. Try to remain happy and have patience.

I would advise NMO centres to do more publicity with the booklets they have created and display them in all the hospitals nationally and the work they are doing, Try and even go on BBC TV to talk about NMO conditions and make the Government aware that NMO illness can make people disabled in their everyday lives.

The effect on family/friends

My emotional feeling increased and didn't want to see anyone and didn't want people to feel sorry for me so I stopped seeing family and friends and the pain was making me lose my confidence and my mood was sometimes low and sometimes aggressive, frustrated and fed up with my life.

My children and wife suffered the most as my daughter was getting married and on the day of the wedding I couldn't walk and after the wedding I ended up in back in hospital. My wife suffered a lot as she kept things going and had to look after me and go to work.

Impact of my work

The pain and the symptoms I was experiencing meant I was unable to go back to work.

Impact on my social life/leisure

I lost a lot of my friend as I didn't want to go out anymore with the pain I experienced. I left all my leisure activities like music, gym, art. I just couldn't do it anymore as my pain was so severe.

Impact on my relationships

My wife and children were very supportive and understanding and could not have gone through with everything what was happening to me without them. They gave me a lot of encouragement and support.

Top tips for keeping active and Healthy

My motivation to keep active and healthy was I wanted to get my life back and I had determination of taking any advice the Oxford team would tell me and kept active and healthy by joining the gym. Any physio or therapy I was offered I would attend them. To take my mind off pain I was doing things I enjoyed; most of which were music and art. I joined the art group which helped me express my feelings through art. I enjoyed that as it gave chance to meet new people and socialise again. I also went to do voluntary work with blind people supporting them with art and help with Maths in adult education. Art and math are my favourite activity which I enjoyed doing before my illness.

Things I have learnt along the way

I have learnt that we need to stay positive and think positive and have hope that we can achieve goal if they are set small and achievable and not to give up life. Find something positive to do which will make you happy even if it small. Start small and achieve it. Don't set your goals too high and get disappointed when you can't achieve it. The pain we experience will always be there nothing bad will happen to you when we are in the most experienced team at Oxford.

How I cope on a daily basis

I make a small achievable plan. I keep a diary of the day and I try and achieve two things from it. I plan my routine based on each day on how I feel. If I am in a lot of pain I will rest and try again when I can but I didn't give up. My wife was there to encourage me and support me. She would tell me what to do what I can do and monitor my wellbeing.

Tips for getting through the week

Plan some positive activities which are achievable and include your wellbeing activities. For example: rest, exercise, diet, mind fullness.

What I would like to say as a way of keeping positive and getting the most out of life...

I have learnt how to deal with my illness and work on my needs regarding my wellbeing to pain. Sometimes I just ignore the pain and keep doing things I can do and stay positive and be grateful that I can do things which I could never have imagined I was able to do. I try and find an alternative activity to overcome some of the pain I experience in my legs and feet. I compromise by buying the right tools and foot wear to still do things I want to do. For example my feet hurt me so I cushion my shoes, my sleepers, water activities I wear water shoes and use a lot of padding to make my feet comfortable and still carry on walking on the beach, go for aqua gym. I still go to gym and pool but I will choose activities which will not provoke my pain. I would advise that stay positive and keep moving and watch your diet and rest when you feel tired and ill but don't give up. There should be more awareness of NMO amongst doctors, hospitals and public perhaps through media.