

From an NMO patient to other patients

My dear friends, just a little encouragement from me on how I cope and stay positive with my illness and how I cope life every day. I have had NMO for over 8 years now and I am so fortunate I have had no relapse.

I know how this illness can be so harsh. The first reaction is one of shock. It feels like the whole world has turned upside down and all those things you have planned to do have gone out of the window. It took me a while to come to terms with it. I tried not to reflect on how or why this has happened to me. Think positive and think right this has happened to me and I can't change it so what can I do with what I have to move forward.

I now adjust my discomforts by finding ways I can heal and cope with my pain rather than increase my medication. My wife and I decided that the pain will always be there and no one can take it away so we stayed positive and keep trying different methods to encourage my own independence and staying positive. I found that distraction helps, keeping your mind busy. I took up some hobbies like painting, learning musical instruments, gardening, doing puzzles etc.

I have now changed my thinking so that I can cope with my life. I am very aware that I will experience a lot of discomforts in my life but that I want to be able to be happy and enjoy my life with my family.

I change my activities to suit me. I stay positive by doing mindfulness, yoga, pilates, go to the gym and stay active with exercise which I can manage. I have lots of different footwear with insoles to encourage me to walk. I choose exercises which don't create pain and fatigue. I rest when I am tired. I plan activities everyday which are manageable and set small achievable goals. Balancing your energy, pacing yourself is very important, not to overdo things to avoid fatigue.

The most important thing is to work as a team with your partner and family. Staying together and helping each other and I encourage my family to support them too to stay positive because they have had great impact of this illness too.

I now have a grandchild which my daughter face-time me every day this helps me with my moods when I have bad days. Change of scenery is very positive way to cope with low moods. Go to country park see nature. My wife encourages that to me every day. It is important to watch your diet and eat healthy food.

Than you to my NMO team at Oxford to get me where I am. If it wasn't for their encouragement and support I wouldn't have made it. They all treat you with respect and dignity. Stay positive and stay brave my friends. I pray to God that things will improve for us and the research will help us find the cure for this illness.

Thank you for listening to me and thank you for reading this message.

Naresh