NMOSD AUSTRALIA

Advice to others

Within this information sheet are quotes from patients previously diagnosed with NMOSD and results from the 2020 Australian NMOSD PEEK study

The patients that participated in the 2020 Australian NMOSD PEEK study spoke about the importance of peer-to-peer information sharing. The information below represents the insights that patients diagnosed with NMOSD, would like to share with others in the future.

What people diagnosed with NMOSD wished that they had known earlier

In the in the 2020 Australian NMOSD PEEK study, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6,33.33%).

Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

I suppose everything I know now, I wish I'd have known earlier. Probably the very first time-- When I got the phone call of NMO, it would have been good if that doctor could have pointed me in a direction of some particular information rather than me-- Or even when they first sent the blood tests, and sent me for the blood test. If there was somewhere or some information he could have sent me to, instead of me having to go through the minefield of everything in the world, rather than-- Just so that there was a basic grounding of NMO rather than it being this humongous thing that some people do die of, and some people get vomiting, and some people get choking, and you're like, "What?" Just a basic information would have been good when you first get told NMO. Participant NMO_006

Yes, it was pretty grim. When I was diagnosed, they really didn't know very much. The statistics were really bad. The prognosis was particularly bad. In a way, I just thought, "Well, things are going to turn to shit in the next few years. Maybe don't bother doing-- It's just not going to be good," but that wasn't the case at all. I'm doing really well. Probably if I had a realistic picture from the beginning, it would have been better. Participant NMO_010

Definitely. I wish I had have known that this disease was actually what it was at the initial diagnosis. Participant NMOCA_007

Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration

Yes, definitely. I definitely would have read more after my first diagnosis online to find out that, "Hey, there are people who do regular infusion treatment, just to prevent from relapse." Which I didn't know. Even though at six months, when I did the blood test, I was by then, I was like, "It's six months already, how come I'm not getting an infusion? And I asked the doctor. The doctor goes, "Oh, your antibody cell's not up yet." By the time it was nine months, I already had my relapse. I would have a pushed if I'd heard more and more people say they do regular top-ups regardless. I would have pushed for my neurologist to probably give it to me. Then maybe my relapse will be avoided, I don't know. It's hard to tell but I would have pushed, yes. Participant NMO_001

The only thing I think would have been the very first time when I went to the hospital and they sent me away. If I had have known about plasma pheresis. I had the steroids when I went back, but if I had have known about plasma pheresis, I would have asked for it sooner and I think it would have saved my eyesight because that's what did save my eyesight. I would have had both eyes I think, if it hadn't have been left for as long as it did. At the same time, I know there's so many things you can't just go in. It's very difficult. I get that, too. Participant NMO_011
Probably to take IVIG the first go. Participant NMOCA_005

Participant describes wishing they had known to ask more questions and advocate for themselves more

100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness, I think. Participant NMO_005

Yes, and also when I got the infection, I would have pushed harder to force someone to listen to me and I probably should have called in NAME's Rule because I knew I was sick, but I started to doubt myself. I started losing my confidence and I should have called, because I knew. My background is in PROFESSION and I've always worked in hospitals and stuff like that. I knew that something was wrong and I should have pushed it. Participant NMO_011

Yes. When it first all happened, I wasn't probably strong enough now that this has happened to me to push more and find out. Yes, it's quite hard because if I would have known what I know now, I could have gone to the doctor and said, "Oh, look, I know that I'm a CD19 CD20. A lot of people don't even know what CD19 and CD20 is. Virtually, yes. The levels of what's happening, they tell you it's MS, and it's not MS. I had different things. They opened up my spine, which I wish they didn't. I think they've done damage that way. If I would have known what I know now to when it first happened, I probably wouldn't. I would have been in a different situation. Participant NMO_013

Would this have influenced your decisions

Participants were asked the follow-up question "would this have influenced your decisions," the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

Participant feels that this would have influenced their decisions

100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness. Participant NMO_005

Yes, if I had have known about—not that if I hadn't have known about rehab because I knew rehab was there but what things would have made it easier in the beginning to avoid the weight gain and things like that. Participant NMO_014

Definitely if we knew that she had a spinal cord injury it would have made a huge difference to knowing what services to reach out to. Participant NMO_016