



NMOSD AUSTRALIA

Decision making

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

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness¹. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare^{2,3} highlighting the importance of healthcare professional communication.

Important aspects of health-related decision making for the participants in the 2020 Australian NMOSD PEEK study were side effects, efficacy, and cost. Approximately a third of participants felt they did not have the opportunity to take part in decision making for the treatment and management of their condition, and only about 20% of participants felt they played an active role in decision making. The participants displayed a willingness to take part in decision making when it comes to deciding how their condition is managed, especially as they feel more informed and assertive, and are aware of their own health and limitations

The role of family members in decision making is important, with many making decisions following consultation with family⁴. In the 2020 Australian NMOSD PEEK study, participants with NMOSD did not discuss the role of their family in decision making, however, 30% of family and carers discussed taking an active role.

Discussions about treatment

Participants in the 2020 Australian NMOSD PEEK study were asked to recall what treatment options they were presented with and how they felt about such options. The most common was participants being presented with multiple treatment options and this was described by 11 participants (61.11%). This was followed by participants being presented with one treatment option (n=6, 33.33%). Below are some examples of positive interactions at diagnosis where options have been discussed in a supportive way, and taking into consideration what is important to patients.

There was a lot of discussion about safety and efficacy of the various medications that were available, and the three of us made an informed decision about which ones to trial. The neurologist, the professor was basically saying, "Look, it might take a few goes to find the right one for you so, I think you should start with this one and then move on to that one and we'll just see how you go." We had lots of discussion about which ones. Participant NMO_016

Because I travel every year, I travel solo and I still visit people within NMO, I plan my journey, I'm determined to live my life really fully. Even though- because I had to walk away from teaching, I was always passionate about camping. That's why I go and do that. I've now got a partner that I can do it with, but for four years, I did go solo on short and long trips all around Australia on the Mycophenolate. He didn't want to put me on Rituximab because of the fact that I like to travel. Participant NMO_004

Decision-making over time

The way that you make decisions might change over time as you learn more about NMOSD and become more assertive.

Participants in the 2020 Australian NMOSD PEEK study were asked if the way they made decisions had changed over time. There were 16 participants (88.89%) that felt the way they made decisions about treatment had changed over time.

Participant describes decision-making changing over time

It's changed as I've learned a lot. When it first happens, you get a bit overwhelmed by it all, but I've had to teach myself, learn a lot in the nine years. If you don't learn a lot, you don't know what's happening. Participant NMO_013

No, definitely it has changed. I recently did a deep dive into what NMO is this year. Just previously I feel like you've got to be asking lots of questions and you can't with just your 10-minute session with your specialists. Participant NMO_002

No. Definitely changed after. Now, I'm researching a lot about a massive decision. I'm not just like, "Yes. Let's decide" I'm more researching and asking for advice, so I've definitely changed the way...No, definitely changed. Participant NMO_005

Participant describes no change in decision-making over time

Same way. I think we are quite too early in this journey to have made any other decisions in this. I think if we went 10 years down the track, I think we probably would have changed but now it's just 18 months. Participant NMOCA_003

Where participants in the 2020 Australian NMOSD PEEK study had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=6, 33.33%).

I don't trust doctors as much as I did at the start. I trust my own research more now, definitely. Participant NMO_005

No, definitely it has changed. I recently did a deep dive into what NMO is this year. Just previously I feel like you've got to be asking lots of questions and you can't with just your 10-minute session with your specialists and to see whatever they say. You got to ask questions. You've got to look into things like diet and exercise because you know all that stuff. I don't whether it's just seen as heeby jeeby stuff that specialists don't touch. They don't touch it. They touch diet. I think there's a lot out there that could be explored especially with inflammatory diseases and things like that. Participant NMO_002

It's changed as I've learned a lot. When it first happens, you get a bit overwhelmed by it all, but I've had to teach myself, learn a lot in the nine years. Participant NMO_013

Personal goals of treatment or care

When you are diagnosed with any condition, one important conversation to have with your treating clinician is about your own, personal goals of treatment. This can help open a dialogue about access to allied health and other supportive care health professionals, and ensure that you have a holistic care plan.

Participants were asked what their personal goals of treatment or care were. The most common response was participants wanting to maintain their condition/prevent worsening and relapse of their condition (n=7, 38.89%).

I think he just knows I don't ever want to be in a wheelchair. I don't ever want to be incontinent and I just don't want to be affected by it, which is a bit unrealistic, but that's my goal. Participant NMO_003

Well, just as long as my treatment keeps working, that is the main goal to try to keep my life as good as it can be at this moment in time, which I don't feel like it's a life at all. [chuckles] I'm still battling with life in general. Participant NMO_012

What is difficult sometimes for me to understand, and is very frightening, is that I could never tell if I was just having a flare or I was having a relapse. I have had a relapse and I've had many flares, and because it's so hot up here, if I'm outside for too long, my vision starts to disappear, so I've got a lot of aids that help me. I've got a talking microwave. Participant NMO_011

Decision-making and personal goals of treatment reflection

This is a list of questions that may help you through the decision-making process at any stage, whether you are newly diagnosed or simply re-evaluating your goals of treatment. These are all questions to support shared decision-making with your treating clinician and aim to help you reflect on what is important to you. The first questions are questions that you can think about before a consultation, and the second set is what you can ask when you meet with your treating clinician. Following this checklist are some more quotes from others diagnosed with NMOSD about their treatment goals.

- Describe the main challenges or concerns that you have at the moment.
- What are some of the main concerns that you have about the future?
- If you were able to reduce the impact of NMOSD, how would you know that things are better, that is, what do you need to feel and see improvements in?
- What are three goals that you would like to work on in the next 12 months in relation to your condition?
- For each of these goals, how will your life be improved if you achieve those goals?
- What are your limitations in relation to treatment and management of NMOSD, that is, is there anything that you are not comfortable with or nervous about in relation to treatment or management?

Decision-making and personal goals of treatment question checklist

- Can we review where I am at in relation to progression of my NMOSD and what to expect in the next few years?
- I've been thinking about my own goals of treatment. Can we have a chat about what is realistic and whether there are any adjustments to my care plan that might be possible to help be achieve those goals?
- Can we review where I am at in relation to progression of my NMOSD and what to expect in the next few years?
- Are there any new treatments or management for NMOSD that have emerged since my last appointment?
- Can we review my treatment and management plan and just make sure that I have access to the different allied health professionals that are needed?

What needs to change to feel like treatment is working

Participants in the 2020 Australian NMOSD PEEK study were asked to describe what needs to change to feel like treatment is effective. The most common response from six participants (33.33%) was needing to see a reduction in the symptoms of their condition. This was followed by needing to experience an improvement in pain levels (n=5, 27.78%).

Participant describes needing to see a reduction in symptoms of the condition to feel as though treatment is effective

No. I'm at that point in my diagnosis where I'm not really expecting any more improvement. I'd like my bladder to work better. Participant NMO_010

As I said to you, I feel like when I'm walking, my body's so tight, and it's quite depressing type thing that when you're walking around, you feel like something's squeezing your legs and all that. If I can get a medication or sometimes if I take a Valium or Lyrica, it may help settle the nerve down. Then it's a lighter feeling. Participant NMO_013

It's just the reduction in what you've been prescribed to take it for. So looking into the muscle cramping and stuff like that. It seemed to work, but then it got worse, so I knew it wasn't working for me. Participant NMO_014

Participants reported needing to experience an improvement in pain levels

Well, I suppose being able to move without pain. Being less stiff. Medication treatments only do like pain and stuff and just stop the flares. Participant NMO_006

For me, it was mostly with my eyes. If there were, for example, side effects that were not mild side effects, I would deal with them if I could tell that they were helping my eyes where I wouldn't have pain in my eyes or no blurry vision. For me, if I start getting pain, I would first increase my steroids, but if that doesn't help, then it means the immunosuppressant doesn't work. Participant NMO_005

Yes. That's a reduction in the pains that I'm getting and things like that. Leading up to my infusion, I was starting to get more symptoms, but they seem to have eased since I've had it. Participant NMO_008

Participant describes needing to prevent relapses and/or worsening of their condition to feel as though treatment is effective

For me, for the treatment to work, I think rituximab whether it works then if I don't relapse then I will believe it worked. Otherwise, no. [laughs] I'm still yet to see what will happen next. Participant NMO_001

Basically, yes, when I'm not having a relapse, it's a good day. Participant NMO_003

Goodness. I don't know. With the Rituximab, it was just going from week to week and just hope you didn't relapse. We still don't know. At the moment it's holding with Rituximab, but it's still-- And they say as well, it's a hope because there is no drug really out there so far that is just designed for NMO. Participant NMO_012

Participants reported needing to experience improved mobility

I think it was quite dramatic going from azathioprine to mycophenolate because I wasn't able to walk far at all, when I was contemplating life in a wheelchair just to get around to within a matter of a month later of being on mycophenolate, being able to walk 20 minutes. That was quite dramatic for me, the ability to walk. Participant NMO_004

As I said to you, I feel like when I'm walking, my body's so tight, and it's quite depressing type thing that when you're walking around, you feel like something's squeezing your legs and all that. If I can get a medication or sometimes if I take a Valium or Lyrica, it may help settle the nerve down. Then it's a lighter feeling. Participant NMO_013

Mobility, being able to move his arms and legs. Participant NMOCA_002

Participants reported needing to experience a reduction in vision issues

For me, it was mostly with my eyes. If there were, for example, side effects that were not mild side effects, I would deal with them if I could tell that they were helping my eyes where I wouldn't have pain in my eyes or no blurry vision. Participant NMO_005

See if something happens with my eye, I won't know until it really affects the part where I can see through because there's been times where I've had pain in my eye. There's been other times where I just lose the vision five days later then I lose the colour. So far we just keep praying every day. Participant NMO_012

Now, they giving her the IVig. I find this one is the better one. I know for the IVig helps her to get her vision back. For me, that's what I want from that. Participant NMOCA_006

What would it mean if treatment worked

Participants in the 2020 Australian NMOSD PEEK study were asked what it would mean for them if treatment worked. The most common response from six participants (33.33%) was allowing them to engage more with social activities and family life.

Participant described treatment allowing them to engage more with social activities and family life

If I didn't have fatigue, I would probably be able to spend a lot more energy with my children. There's some days where I just come home from LOCATION and go straight to bed at like 4:00 O'clock, and my partner kind of has to pick up the slack a lot just because I don't have the energy. Participant NMO_003

It would then help with the fatigue because I wouldn't be as tired and fatigued from doing the smallest simplest thing. Then I'd be able to spend more time with my grandchildren without being completely exhausted and not feeling like I'm a capable Nana and being able to look after your own grandchildren. Being able to go out with my husband without having to plan that I go out in the morning and not the afternoon because I get too tired by the afternoon. Participant NMO_006

Participant describes treatment allowing them to do everyday activities/ return to normal life

I'm obviously retired. The treatment is that I have a cleaner now coming. I can only virtually do something for an hour or so, and then I have to stop. Then start again and stop, to relax the body down. If I'm doing something, like doing a little bit of housework or whatever, I virtually have to do a little bit and then my body all plays up and the nerve sensation, everything just goes out of whack. I used to play golf, do all those things, which-- That's what I'm trying to say. Yes, it'd be lovely if I could be normal again, but it's not going to happen because my spine is damaged, and whatever I do, even the pain doctor said, "may work, may not work". In all my trials and different things that's happening, they give me that option of, "We can try it. It may work for you, or it may not work for you." They can't say to me, "This is a super drug that's going to work." Participant NMO_013

Probably not lean on my husband so heavily for chores around the house. We have our grandchildren every Friday. NAME GRANDSON's four now the youngest, so it's not too bad. You feel you're not pulling your weight. Neither of us is getting any younger. That's probably the thing for me, it's being out to do my share of the workload in a timely and appropriate manner, not having to do a job over three days, but actually just doing it an hour. Participant MOG_001

Participant describes treatment allowing them to have an increased mobility/independence

That I can still see or I can still walk. It's just those things. I'm grateful for that I can still see something. As well as still walk and be able to pick up things. Participant NMO_012

I'm able to go outside and walk in the dark and actually see on the floor and see the waves crashing in the water. I couldn't do that when I was on rituximab and stuff. Yes. That's something that I see is a massive improvement. Yes. It made me really look forward to every single day so it's definitely something I want to stick to. Participant NMOCA_005

The ability for treatment to give my life back to me. Even though I have a fantastic life now, then I've made it so that way, it would give me stamina, it would give me the ability to walk and hike for much longer. Participant NMO_004

Participant describes treatment allowing them to return to work

Well, obviously, I haven't been able to work. I can't work because I don't have the stamina anymore. Even one phone conversation will exhaust me. The ability for treatment to give my life back to me. Participant NMO_004

Being able to go back to work, that sort of thing. Participant NMOCA_002