



Information and communication

NMOSD AUSTRALIA

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

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving¹. Components of self-management include information, activation and collaboration¹.

Patient activation is measured in the 2020 Australian NMOSD PEEK study using the Partners in Health questionnaire²⁷. The NMOSD participants in this study had good scores for knowledge, recognition and management of symptoms, very good scores for adherence to treatment, and moderate scores for coping.

Information is a key component of health self-management^{3,4}. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management^{3,4}. These are all important areas to discuss with your treating clinician.

The most common types of information given to participants in the 2020 Australian NMOSD PEEK study were about treatment options, and disease management, however, about a third of the participants had little to no information given to them by their healthcare professionals.

The type of information that participants in the 2020 Australian NMOSD PEEK study searched for independently most often were disease management, disease cause, complementary therapies, and treatment options. Half of the participants looked for information about dietary information, and physical activity.

Regarding access to information, participants in the 2020 Australian NMOSD PEEK study had preferred online information, speaking to someone or a combination of both. In this study, participants with NMOSD looked for information on the internet in general, on Facebook, and through the Guthy-Jackson Foundation. Journal articles, treating clinician and other patient's experience were noted as important to some. In terms of timing of information, again, PEEK participants benefited from information at different times, from the time they were diagnosed, sometime after diagnosis

1. In: Adams K, Greiner AC, Corrigan JM, eds. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. Washington (DC); 2004.

2. Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Qual Life Res* 2010; **19**(7): 1079-85.

3. Grande SW, Faber MJ, Durand MA, Thompson R, Elwyn G. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient Educ Couns* 2014; **95**(2): 281-7.

4. Taylor SJC, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. Southampton (UK); 2014.

Access to information

Below are quotes from patients about where they were able to find information and you might find some new sites or ways to access information.

In the structured interview of the 2020 Australian NMOSD PEEK study, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

Participant describes accessing information through the internet in general

Mainly Google. I sought out possible causes. I sought out whether vaccines have anything to do with it. That's just recent. I sought out diets that might be good. That's just recent too. Participant NMO_002

Pretty much just the internet and I've joined some Facebook groups of people that have it. Participant NMO_008

Goodness. Pretty much YouTube, Google. There wasn't really that much at that particular time. Just watching I suppose YouTube more so, I got more things out of, but still wasn't that great at that time. Participant NMO_012

Participant describes accessing information primarily through Facebook

The biggest one was to get onto the support page, their NMO support page on Facebook with the registered nurses and just listening to everyone else, and seeing what everyone else was going through, that's where I got all the information from. Participant NMO_009

Most of my information comes through Facebook, on the NMO Australia site and anything related to that, like they'll put up studies and anything that's going ahead. Participant NMO_011

I'm on the Facebook page, the NMO Australian website. There's a lot of people with NMO who are on there. Participant NMO_015

Participant describes accessing information from a specific health charity: Guthy-Jackson foundation

I sought out some information from the Guthy-Jackson Charitable Foundation. I don't know if you've heard of them. They're pretty big. Participant NMO_002

It was purely while I was in hospital, I happened to find the Guthy Jackson. Participant NMO_006

Mostly the Guthy-Jackson Foundation in the States we could say were the first NMO-- Anyone in the world that was like a foundation for NMO. Participant NMO_016

Participant describes accessing information primarily through journals (research articles)

Medical journal, NMO support group. Back then I haven't had to sign up but I never really read anything because I didn't want to read too much and then think too much. Participant NMO_001

I try my best to read-- It takes me a while with my eyes, but to read like research articles from medical journals. Participant NMO_005

More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO_010

Participant describes primarily accessing information through treating clinician

The general information that I've mainly got is through my MS specialist, and on the internet, and the Guthy-Jackson Foundation, actually. Participant NMO_004

When I was first diagnosed, I looked for information everywhere, my neurologist, my GP, online, and there really wasn't anything available. Participant NMO_010

My neuro immunologist and neurologist gave me really good information and they sat me down a few times for a few hours and just basically went through everything, but it's the nurses when I went to have any infusions, so they were really good in the department. Participant MOG_006

Participant describes primarily accessing information through other patient's experience

I'm also in a group on Facebook where people write about themselves, or any treatments, or anything new that's coming up, so it's mostly all been from me looking on-- I guess, on the internet. Participant NMO_005

The biggest one was to get onto the support page, their NMO support page on Facebook with the registered nurses and just listening to everyone else, and seeing what everyone else was going through, that's where I got all the information from. Participant NMO_009

More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO_010

Information that was helpful

In the structured interview of the 2020 Australian NMOSD PEEK study, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by seven participants (38.89%) was other peoples experiences.

Participant describes other people's experiences as helpful (Peer-to-peer)

Knowing that there's somebody else with it was quite good. That was the best thing for me initially. I suppose it was knowing that people don't die from it. Some people have died from it but it's not the predominant type thing. That there is other people that have been in this situation and it was good to speak to them. That there are some things to do for bladder and for bowels and stuff like that, that other people have written about because it had already happened to them. Participant NMO_006

Putting your mind at ease that you're not alone. That's probably been the biggest one, also certain treatments, some treatments work for some people, I know it doesn't work for others it doesn't yes, but it just gives you peace mind where you can go and research and then see what other treatment's been done and what I might be able to suggest to a neurologist and yes, things like that. Participant NMO_009

Usually the other patients. Participant NMO_014

Participant describes talking to their doctor or specialist as helpful

I think the most helpful was, to be honest, probably first would have been my MS specialist and then second was the Australian Facebook Group. Participant NMO_004

I went and saw, actually I did go and see a neurologist in LOCATION METROPOLITAN. The information that he sent back through was the most informative about my condition. Participant NMO_008

Probably the most helpful would be my old neurologist. He was exceptionally good. He would sit down and discuss with me if I have a query or anything that was not right. Participant NMO_013

Participant describes information specific to their condition (and sub-types) as helpful

More management plans. Knowing about the different types of NMO, what are the effects, whether is a one-off thing, whether it's relapsing form and management plan. What sensation will come up and that kind of stuff, yes the symptoms? Residual symptoms, mainly residual symptoms because I need to work out whether is it residual symptoms or is it a relapse or whether I need to go to hospital. Actually, it's that kind of thing that sort of help me. Participant NMO_001

Probably, I just think sometimes NAME DOCTOR puts up webinars explaining in layman's terms how the water channel works and how this works and that. I find that good because you're seeing it and people can ask questions. I guess once you've got the diagnosis, you've got the treatment, and you're fine, there's not much more. Unless there's new research coming out, there's not a lot of changes, I guess. Participant NMO_015

I think it's the one explaining the NMO and what could happen. Participant NMOCA_006

Information that was not helpful

In the structured interview of the 2020 Australian NMOSD PEEK study, participants were asked if there had been any information that they did not find to be helpful. The most common response was that no information was not helpful (n=6, 33.33%)

Participant describes no information being not helpful

No, not really, because a lot of people have different symptoms or different side effects. Some people get it in their spine and so far, touch wood, I've only had it in my eye. Participant NMO_007

No, not really, especially the Facebook page that everything's positive, I think it's run by two nurses on there as the admin and they watch what everyone says, but yes, everything's been good.. Participant NMO_009

No, not really. Participant NMOCA_006

Participant describes feeling confident in deciding if something is not helpful (or not credible)

I've avoided those things. If I found something, especially in the early days, if I found something that was quite negative, then I would not continue reading that because I wasn't going to allow myself to get into a situation of the doom of it because there was no point, because there was no option. I'm that kind of way inclined and online there are some very upsetting situations and when you're early diagnosed, it's good to avoid that. I think that-- I don't know. I think I'm somebody who would-- I take the positives out of just about most of the things I can find rather than the negatives. Participant NMO_006

No, not really. Yes, not really. I think probably with Facebook pages, people put up their stories, their experiences, and ask questions. Maybe, I don't know, I think you need to take what you can from that. Participant NMO_015

I don't think so. As I said, she's selective in what she researches. She's not into populist treatments, if you like, from our alternative people. Participant NMOCA_004

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support^{3,4}. Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction⁵⁻⁸.

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making⁹

Building a relationship with patient, families and support networks is fundamental to establishing good communication⁹. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding⁹. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands⁹. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources⁹. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

In interviews with 15 participants with NMOSD from the United Kingdom, a common theme of negative encounters with healthcare professionals was reported. This was mostly due to a lack of knowledge, resulting in treatment delays¹⁰. Similarly, most participants with NMOSD in the current study had a negative experience of communication with healthcare professionals. This was because health care professionals had limited understanding of NMOSD, dismissive, or just very limited.

Positive communication in the 2020 Australian NMOSD PEEK study, was usually a result of a two-way supportive and comprehensive conversation between patient and clinician. This was also reported in another study, where participants appreciated honesty alongside health professionals listening to their needs¹⁰.

Communication and collaboration with healthcare professionals was measured the 2020 Australian NMOSD PEEK study by the Care Coordination questionnaire¹¹. Participants had moderate scores for navigation of the healthcare system, and they rated their overall care as good, coordination of care as moderate. They had a poor score for communication with healthcare professionals.

Healthcare professional communication

Below are some examples of where patients with NMOSD have had positive communication with their treating clinician to demonstrate what good communication looks like.

Participants in the 2020 Australian NMOSD PEEK study were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

In general, they're quite intrigued. If I see a new doctor, they want to know, and they say, "How did you present? What was it like the first time?" I haven't had too bad a journey with it, but mainly, a lack of info. Oh, sorry, the other person I did get to see was the ophthalmologist. I was under the care of an ophthalmologist, I forgot to mention that. It was funny because he was having a lecture the next day on NMO and he asked me to look at his notes [laughs] to see how accurate they were. It's educating the medical community as well. Participant NMO_004

It's been all good, all been absolutely positive, a lot of the general practitioner and my local doctor, he does it all day, any of the doctors I've seen, the GP's that they don't seem to know much about it at all. They generally have to look up the condition to find out, but the neurologist have obviously been brilliant and my physio, like I said, who knew nothing about the disease he studied for days about the disease. Participant NMO_009