



NMOSD AUSTRALIA

Treatments

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

Treatments

Acute treatment of an NMOSD attack consists of high dose steroids for five days, oral prednisolone then continues for weeks, reducing over the course of months. Plasma exchange is used when improvement is not seen within days of high dose steroids^{1,2}. Plasma exchange has been shown to be more effective in improving recovery following relapse compared to high dose steroids, suggesting that escalation to plasma exchange may reduce long term disability in NMOSD^{2,3}.

Progression of neurological disability in NMOSD is thought to mainly occur during clinical attack/relapse⁴, suggesting that preventing clinical attacks is the most important therapeutic target in NMOSD⁸. Management of NMOSD consists of preventative immunotherapy treatment, monitoring safety of treatment and adherence to treatment⁵. Immunosuppressive treatments reduce but do not stop relapses, however, they may reduce the disabling effects of optic neuritis and transverse myelitis⁶. Relapse prevention therapy is recommended for all patients that are AQP4 positive, and for AQP4 negative patients with established relapsing disease⁷. Following relapse, it is recommended to switch to a drug with a different mechanism of action, combination therapy is an option but data is limited⁵. Disease modifying drugs used in multiple sclerosis have been shown to with not work in NMOSD or may exacerbate NMOSD and should be avoided⁸⁻¹⁰

The most common prevention therapies used include azathioprine, mycophenolate mofetil and rituximab resulting in relapse free rates of between 25% and 66%¹¹⁻¹⁶. Oral prednisolone is often given long-term, as the combination may be more protective than mycophenolate mofetil or rituximab alone¹⁷. Other immunosuppressants that are occasionally used include tocilizumab, methotrexate, cyclophosphamide, mitoxantrone, intravenous immunoglobulins, tacrolimus, and ciclosporin¹⁷.

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Summary of treatments for NMOSD

Acute treatment

- [High dose steroids](#)
- [Oral prednisone](#)
- [Plasma exchange](#)

Preventative immunotherapy treatment (may be used in combination with oral prednisone)

- [Azathioprine](#)
- [Mycophenolate mofetil](#)
- [Rituximab](#)

Occasionally used immunosuppressants

- [Tocilizumab](#)
- [Methotrexate](#)
- [Cyclophosphamide](#)
- [Mitoxantrone](#)
- [Intravenous immunoglobulins](#)
- [Tacrolimus](#)
- [Ciclosporin](#)

Note: links above are given to the consumer medicine information leaflets available from [NPS Medicinewise](#). The links are given for general information and may not reflect the dosage or form prescribed.

Allied health

There is little published information about the use of allied health to manage NMOSD. In the 2020 Australian NMOSD PEEK study, 61% of participants with NMOSD used at least one allied health service in the management of NMOSD. As NMOSD is a progressively disabling condition, there is a gap in services for this cohort. The most common allied health services were occupational therapy (56%), physiotherapy (50%) and psychology (44%), participants found these moderately effective to effective.

Lifestyle changes

There is little published information about lifestyle changes in the NMOSD community. In the 2020 Australian NMOSD PEEK study, 83% of participants with NMOSD made at least one lifestyle change, most commonly exercise, and diet changes. Exercise was used by participants for both their mental health and physical health. Information about lifestyle changes was not given to many participants, one participant was given information about exercise, and no participants given information about diet. More than half of the NMOSD participants searched independently for information about diet and/or exercise. There is clearly interest in lifestyle changes for the management of NMOSD, and a need for more information.

Complementary therapies

There is little published data about complementary therapies in the NMOSD community. In the 2020 Australian NMOSD PEEK study, over 75% used at least one type of complementary therapy, the most common types were mindfulness or relaxation techniques, supplements, and massage therapy. Participants were given no information about complementary therapies, yet over 60% searched for information independently. More discussions are needed in this area so that people with NMOSD can safely use complementary therapies alongside their other treatments.

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 9 February 2021. The search included any study that included NMOSD participants, was conducted in Australia, and began recruitment at any time. A total of four studies were identified that had a target recruitment of between 56 and 231 participants, all studies were international studies with Australian sites in NSW or Victoria. Currently, only one study is recruiting.

The Australian New Zealand Clinical Trials Registry can be accessed [here](#), where clinical trials can be searched for by condition and location. For people with NMOSD, clinical trials may be available for symptoms, for example, optic neuritis, myelitis, and brainstem syndrome.

All participants in the 2020 Australian NMOSD PEEK study reported having IV high dose steroids. Other treatments commonly used were rituximab, prednisone, and plasma exchange. Very few were treated with azathioprine, mycophenolate mofetil, and methotrexate.

Few participants in the 2020 Australian NMOSD had discussions with their doctor about clinical trials, and no participants had taken part in a clinical trial for NMOSD. However, there is a willingness to take part in a clinical trial (89%).

Side effects and symptoms

NMOSD affects people differently. There are a range of mild and severe side effects and you may relate to some of the descriptions below. This information is intended to help you identify any side effects or symptoms that might be troubling you, and think about how you might describe these to your treating clinician to discuss. The first quotes below refer to mild side effects.

Symptoms are often listed in information about a condition, and side effects are listed from treatment. To help understand the impact of side effects, people with NMO have described what mild and severe side effects mean to them. In the 2020 Australian NMOSD PEEK, mild side effects were described as those that can be managed and don't interfere with daily life. Some examples of mild side effects were spasms, numbness, and neuropathic pain, nausea, gastrointestinal distress, fatigue, and headaches.

Side effects that can be managed and don't interfere with daily life

I don't know. If I could keep working or keep doing the things that I enjoy even with the side effects, I'd say they're kind of mild. Participant NMO_010

For me, mild is something that I can live with and I can deal with. Participant NMO_005

Numbness/paresthesia (paresthesia is an abnormal sensation of the skin like tingling, pricking, chilling, burning, and numbness)

No. That's okay. I wake up with a lot of numbness. I have hip pain. I have burning in my feet. I do get headaches randomly and a very sore neck. There are so many things but they're mild things that I-- Sometimes the vision is-- you can feel the pain behind my eye but it's not-- I do worry but it's not severe as such. Participant NMO_008

Pins and needles. If they are just locally that's a mild side effect as well as-- I think that would be the only-- Then there are some kind of more sharper pains every now and then but they are very seldom but they take place. I would put them also in the mild category. Participant NMOCA_003

Fatigue/tiredness

Oh God. Where do I start? Mild side effects. Tiredness, I would say. A little bit tired always. Tiredness, a bit of-- I don't know, sensation. Right now I'm experiencing burning sensation. I guess for my first diagnosis, my residual side effect was actually quite minimal. It was just a bit of burning sensation here and there, not all the time on my back. From this recent relapse, the sensation is much bigger. I've got numbness on my right side of the torso. I have vibration in my legs. Those side effects, sometimes I felt like I'm not emptying- feeling constipated sometimes. It's just that kind of sensation. Participant NMO_001

Yes, I get very fatigued from the medication. I get very fatigued, and I feel very run down for a few days post. That's pretty much it really for mild, yes. Participant NMO_003

Neuropathic pain (caused by nerve damage, this can feel like a shooting burning pain)

It varies and changes daily. The electric shocks and I call them tremors, my body tremors like it's inside. It feels like it's trembling the whole time. Constant severe burning through my whole right-hand side and left side. Pins and needles severe. I have a lot of, I can't think of the term, where it's like electric shock goes down my leg and I can't control my leg. It just kicks out. Yes, a lot of, I think they call it banding or hugging, severe hugging right down my right-hand side. It feels like my whole right leg is being cast in plaster. Participant NMO_009

I'll just get a little electrical storm going on. I can get things like-- I don't know what I've got-- I get banding all the time around my middle. It feels like I'm being squeezed. Sometimes it's okay, sometimes it's really bad, but sometimes it can just be mild. Participant NMO_011

For me, mild is sometimes or probably every day, say, I might get a quick sensation of a burning rash on the sides of my body, just in about a three or four-inch square and it will just be a little quick burn, and then it goes. On my left side, it's like I've still got the socks on and my left side's tight, and I get a little bit of just slight pain but nothing that bothers me at all. I just know that it's still there every day on my left leg. What else? Yes, that's my mild ones. Participant NMO_015

Gastrointestinal distress (things like constipation, bloating, reflux, nausea, vomiting, diarrhoea, abdominal pain and cramping)

Those side effects, sometimes I felt like I'm not emptying- feeling constipated sometimes. It's just that kind of sensation. Participant NMO_001

Yes, maybe some confusion, mild pain at the sight, mild bloating, I guess, having these medication". Participant NMO_002

Headaches/migraines

She does get more headaches now. She sees that as part and parcel of NMO and she's okay with that. NAME PERSON CARED FOR recognises her limitations if she's got a task to do and that might be house working, or vacuuming, or something like that. Rather than do it in two or three hours, she might break it up, so it might even take a couple of days to do. She changed her outlook in that regard, which is probably good. She's more recognising of her own limitations. Participant NMOCA_004

For me, mild is something that I can live with and I can deal with. For example, like a headache, I have learned to live with my headaches. Participant NMO_005

Temperature regulation

The mild side effects are the spasms. You get heat intolerance. That's another side effect. I have heat intolerance. I find that once I heat up, it's very hard for me to cool down. That's more nuisance. It's not as severe side effects, but it can lead to me having a flare-up if I can't get it under control, and that's where I do get very, very weak. Mild symptoms are pain, or that sometimes that can be serious Participant NMO_005

In terms of mild would be temperature regulation. He's quite hot and cold. He gets temperatures quite often, sweats, a bit of fever, that sort of thing. He has had blurring in his eyes and double vision and early on he went to the hospital with a headache. Participant NMOCA_002

Pain

I have to cope with the pain. Sometimes it does get me down. With the pain, put it this way, I have been managing it quite well up until now but it's getting worse, it's grabbing my chest. Participant NMO_013

Nausea

Mild side effects to me is something that you can take a pill for and it disappears or it eases, so nausea I can take an anti-nausea tablet and it alleviates it. Participant NMO_017

Skin sensitivity

Well, medication-wise, everything seems fine and that sort. Also, with the Rituximab. I don't know if this is the disease itself, or something that the Rituximab has a part of. It's very sensitive burning skin. Your skin feels like it's sunburned. I've spoken to the neurologists about this and he thought hang on I haven't heard of that before, but now I've spoken to a few people that have got the disease and they go, "No, that's normal" Participant NMO_012

Severe side effects

In the 2020 Australian NMOSD PEEK study, severe side effects were described as those that interfere with daily activities. Some examples are pain, vision loss, fatigue, weight gain and spasticity. Fatigue and pain were described both as a mild and severe side effect.

Other studies have described fatigue as being moderate to severe as it may interfere with activities of daily living¹⁸. Pain was common for optic neuritis¹⁹, neuropathic pain described as severe and disabling. Pain may interfere with activities of daily living¹⁸, and may contribute to fatigue²⁰.

Side effects that interfere with daily life

For me, severe would be something I can't live with. For example, I'm swelling up from my migraines, not being able to open my eyes in the sunlight, things like that. Like being really severely allergic to the sun on some of the medications where I'd go out, for example, to put the washing out, or for taking the washing down, and I'd be covered in a really painful rash. Participant NMO_005

Well, the opposite. The side effects would just be interfering, or if the side effects that are worse than what we were trying to manage, that would be severe but if I couldn't go about my normal day or enjoy things in life, then they would be pretty severe side effects. Participant NMO_010

Pain

The more severe ones, I guess, is the pain. The sudden onset of weakness where I can't speak and I can't move, that's serious. Participant NMO_004

Vision loss

When my vision disappears, usually from overheating, just moving around my body from one side to the other and it's extremely painful. Participant NMO_011

I had double vision that I couldn't cope with. Not vomiting. I couldn't walk straight and severe headache. Did not cope well with any of that. Participant NMO_008

Fatigue

Fatigue, just overwhelming exhaustion, and paralysis from the neck down, and the pain behind his eyes at different stages. Participant NMOCA_002

Weight gain

I think the severe ones would be for me the weight gain because that affects me physically anyway. Then the cognitively, that was not good at all because it's hard when you don't feel right anyway, let alone a medication that seemed to be affecting me as well. Participant NMO_006

Spasticity (tight or stiff muscles that can't be controlled)

Severe side effects are the spasticity which occurs generally at night time. It feels like a massive cramp when my foot will turn round almost 90°, and I can't stop it. I have to get out of bed and just slowly try and put weights on my leg. That can happen on a bad night I figured about 20 or 30 times happening during the night. Participant NMO_009

Treatment question checklist

If you are currently going through the treatment decision making process, this is a list of questions that may help you through the process.

- What kind of treatments are available for me?
- Why do you think I need this treatment?
- Is there a cost for this treatment?
- Will this interfere with any other treatments I am taking?
- How long to I have to take this treatment?
- What are the side effects?
- What can I do to manage side effects?
- What should I do if I something happens to me while taking this treatment?
- Are there any clinical trials that I can take part in for NMOSD or for any of my symptoms?
- What happens if I miss a dose
- Once I start a management plan, will I be reviewed regularly for progress?
- What is the aim of the treatment? To cure, or to control it and manage symptoms?
- How likely is it that my symptoms will get worse or move to other parts of my body without any more treatment? **or** How likely is it that the treatment will improve my symptoms?
- What is the expected prognosis or outcome for this treatment?
- What allied health professionals should I be referred to? (e.g Physiotherapy, counselling/psychologist, occupational therapy, social work, speech pathology)