



NMOSD AUSTRALIA

Quality of life

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

Quality of life

NMOSD has an effect on quality of life^{1,2}, including fatigue and pain that have an impact on daily activities³⁻⁸, and depression and anxiety have an impact on physical and emotional health^{1,4,6,8}.

In the the 2020 Australian NMOSD PEEK, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 16 participants (88.89%) that described a negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included emotional strain on family/change in relationship dynamics (n=12, 66.67%), and reduced capacity for physical activity (n=6, 33.33%).

The information below describes some of the ways other patients have managed their physical and emotional health. If you feel like you need more emotional health support, you can talk to your GP about developing a Mental Health Care Plan.

Regular activities to maintain mental health

In the 2020 Australian NMOSD PEEK, participants were asked what they needed to do to maintain their emotion and mental health. The most common response from six participants (33.33%) was the importance of physical exercise and this was followed by using mindfulness or meditation (n=5, 27.78%).

Participant describes the importance of physical exercise

Exercise and trying to keep my life as normal as I can, when I can. Participant NMO_001

Well, it's really important for me to exercise every day and to get out and walk the dogs no matter how bad I am. If I'm not good, if I'm not having a good day, I take the dogs up to the oval so at least they can get exercise. Being connected with friends, having interests like I do card making and I paint. I've had to reduce my gardening because that's hard to get in on the ground and do gardening.. Participant NMO_004

When I first got sick with all this, it was horrendous. I would have cried every day and I didn't really know what to do about it. It took a few years for me to accept that. Nowadays I do a lot of exercise which actually makes me happy. When I've got an injury, if I can't exercise, then I don't cope very well with my other symptoms. I go to a great counselling session once a month and actually people with MS. I like going to that, but obviously, I'm quite aware that I don't have MS and it's quite different. Sometimes it's a little isolating in the group where I am the odd one out. Participant NMO_010

Participant describes using mindfulness and/or meditation

I do see psychologists. I do see my psychologist and I do mindfulness meditation. I've been meditating for quite a long time and trying to do something that I enjoy every day. Participant NMO_001

Yes. It makes you mentally tired and mentally frustrated when I can't remember words. When I get tired and my eyesight goes when I get tired and that's frustrating. I go to yoga, not necessarily just for the physical, but for the mental fact of being able to switch off for that hour while I'm there. I do meditation. Participant NMO_006

Yes. I personally contemplate, which is like a meditation. I do that at least once or twice a day for 20 minutes. Participant NMO_016

Participant describes consulting a mental health professional

I do see psychologists. I do see my psychologist and I do mindfulness meditation. I've been meditating for quite a long time and trying to do something that I enjoy every day. Participant NMO_001

I go to a great counselling session once a month and actually people with MS. Participant NMO_010

Well I still see a psychologist and I've just actually seen the doctor to get another session of 20 sessions, I think you can have now. Participant NMOCA_005

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

Being connected with friends, having interests like I do card making and I paint. I've had to reduce my gardening because that's hard to get in on the ground and do gardening. Participant NMO_004

The greatest problem is, I don't know whether it's the NMO or with the steroids, I'm very forgetful. I have to write things down, and when either my kids or my wife ask me if I can remember something, I have to write everything down. Participant NMO_007

To look after my mental health, I pretty much just put music on and drown my own thoughts. Participant NMO_012

Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected

It completely effects your mood. Like I have massive mood swings that I can't control, and it's just difficult because everyone's moving forward with their lives around me, and I feel like I'm stuck. Participant NMO_005

I've been very strong, mentally, I always have been, I'm a person who's been able to block things out per se, but deep down I am struggling, I know I am but yes, it's just hard to, yes. Participant NMO_009

As I said, we've been married for 45 years, and the person that you grew up with, and you went through life with, has changed and is reeling from this, so that obviously affects you. It makes me sad, and makes you anxious about the future. Participant NMOCA_004

Participant describes no activities to maintain mental health as their mental health has not been affected

Mentally I'm quite resilient. I get frustrated more than anything at not being able to do some of the things that I used to do or having the stamina to do what I used to do. I liked the very physical labour-intensive thing. Other than that, it doesn't really, you've just got to live with it, if that makes sense. Participant NMO_014

I don't think it really has affected me. I'm quite a strong person, so I tend to handle things pretty well. Participant NMOCA_007

Regular activities to maintain health

In the 2020 Australian NMOSD PEEK, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common way that participants reported managing their health was by being physically active (n=7, 38.89%). There were six participants (33.33%) that described the importance of understanding their limitations and five (27.78%) that described the importance of self care e.g. more rest, support for housework etc.

Participant describes being physically active

I think swimming, so pools opening up here in LOCATION METROPOLITAN would be great because I find when I'm in water, it's much better. Being able to access the gym and having the machines to help strengthen my body is good, being able to get outdoors and walk, connecting with people, making sure that you're not on your own day in day out.. Participant NMO_004

I go to the gym. I try to go to the gym every day, but some days I guess I can't. I just try and live a normal life, and I just try and disregard that I have this condition basically, yes. Participant NMO_003

Well, for me, I meditate, I do yoga, and I go for a walk, and I feel like this is—I see a massive difference, massively changed my life as well. I'm like more calm and I'm more okay with things, so I don't really blow up and I try my best to-- I don't know, be normal. Participant NMO_005

Participant describes the importance of understanding their limitations

I keep a diary and I have to write lists so I don't forget things. I get pleasure out of my dogs, got a couple of dogs. I share them with my brother, he and I share them. If I'm not particularly well or anything like that, he can take them. I try to, when it's cooler, try to go down to the river and take the dogs down there. That gives me enjoyment but I don't venture too far from home because of the heat, mostly. Also, I've got other things to do apart from keeping the home, like of an evening, I need to go out and water garden and do things like that. Participant NMO_011

I have to manage my body, so I have to listen to what my body says. If I push my body too much, it will get worse. Participant NMO_013

I think I have to have insight to when I'm fatigued and I have to stop. That's taken time to learn to stop and rest for a bit, and I'm still learning to do that. I'm pretty bad at that. Participant NMO_017

Participant describes the importance of self care e.g. more rest, support for housework etc.

Make sure I'm well-rested, that's the main thing. I've got to sleep and just plan my day so I don't get too exhausted. Participant NMO_008

Pretty much, if I want to do something in particular, I might just go down the street and just have a bit of a look at the shops. I will make sure that I lay down and just rest, not be stressed, or anything like that, but just rest on the lounge. I don't have to sleep but that's the only way. I've got to really rest every bit of my body, to know, "Okay, I've got to find that energy to reach out to be able to go and do that." That's the only way that I can function. If I know something's coming up that I have to go to, but sometimes it doesn't always help. Participant NMO_012

Sleep, when my body tells me I need to, regular massage, whether it be via massage person or in my massage chair just the compression on my hands, my legs and things like that, just really helps. Just doing the smaller things that I know I can do and enjoy doing. Participant NMO_014

Participant describes the importance of complying with treatment

Well, it's about physio, that's pretty much I do that once or twice a week, obviously I got to do the medication the exact times each day, that was critical, other than that, it's just about the mental attitude and that's being positive and trying to keep pushing forward and doing what I can do each day.. Participant NMO_009

Yes, physio, the ongoing Rituximab. Participant NMOCA_002

I would just make sure that he takes his medication. Participant NMOCA_007