

Section 4

Decision-making

Discussions about treatment

Participants 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%).

Conversations about treatment: Participation in discussions

Of the participants who were presented with multiple options six (33.33%) described being told what to do without discussion, and four (22.22%) participated in the decision-making process.

Conversations about treatment: Specific treatments discussed

Some participants described specific treatments that were discussed, the most common was rituximab (n=11, 61.11%), followed by steroids (n=7, 38.89%), and plasma exchange (n=5, 27.78%).

Considerations when making decisions about treatment

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was side effects as part of multiple aspects that they consider when making decisions about treatment, and this was described by five participants (27.78%).

Decision-making over time

Participants 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.

Decision-making over time

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

Personal goals of treatment or care

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%).

Discussions about treatment

Participants 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%).

Participant describes being presented with multiple treatment options

They said to me that they would...The steroids and then the IVIG and then the plasmapheresis. That's what they've given her. Participant NMOCA_006

I was put on the first line of treatment which was Imuran or azathioprine, so tablets. That was after the first optical diagnosis. Then I was got up to the desired dose. I can't remember what it was, I think it was about 1,000 milligrams or something, and I got pancreatitis and so they thought that- and I was on the oral steroids as well, prednisolone, but they thought it was azathioprine that had caused the pancreatitis, so I was pulled off that. Participant NMO_017

They put me on a high dose of steroids again. Then they put me on CellCept which I had a reaction to

and I actually got, I think they call it pseudogout. My knee puffed up and it was full of fluid and I couldn't walk. I went back to the hospital and they drained that, twice I had to do it and then that settled down, but it was making me very ill as well, so he took me off that. I've been on plasma exchanges and Rituximab and Methotrexate. Participant NMO_007

Participant describes being presented with one treatment option

It was very vague. The hospital just said that they did the methylpred for five days. There was no offer of any other-- like a plasma exchange, or anything like that. Participant NMO_009

Basically that there was none for MS-specific, sorry, for NMO specific in Australia, not on the PBS anyway. I am on Ocrevus. He recommended Ocrevus to treat it, basically. That's what we decided to go with. Participant NMO_003

Pretty much that I was told I just needed one treatment which was an infusion, and I had to wait for approval from the board of the hospital before I could have it. Once they got the approval, then they could put me in for it, and that's rituximab. Participant NMO_008

Table 4.1: Conversations about treatment

Conversations about treatment	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with multiple treatment options	11	61.11	5	55.56	6	66.67	5	62.50	6	60.00	7	77.78	4	44.44
Participant describes being presented with one treatment option	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	1	11.11	5	55.56
Other/unsure/no response	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	1	11.11	0	0.00

Conversations about treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with multiple treatment options	11	61.11	6	60.00	5	62.50	4	66.67	7	58.33	4	57.14	7	63.64
Participant describes being presented with one treatment option	6	33.33	4	40.00	2	25.00	2	33.33	4	33.33	3	42.86	3	27.27
Other/unsure/no response	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	1	14.29	0	0.00

Conversations about treatment	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being presented with multiple treatment options	11	61.11	7	87.50	18	69.23	9	90.00	10	62.50	1	50.00	2	66.67	9	60.00
Participant describes being presented with one treatment option	6	33.33	1	12.50	7	26.92	0	0.00	5	31.25	1	50.00	1	33.33	5	33.33
Other/unsure/no response	1	5.56	0	0.00	1	3.85	1	10.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 4.2: Conversations about treatment (Subgroup variations)

Conversations about treatment	More frequent	Less frequent
Participant describes being presented with multiple treatment options	Moderate to very poor physical function	Good to very good physical function

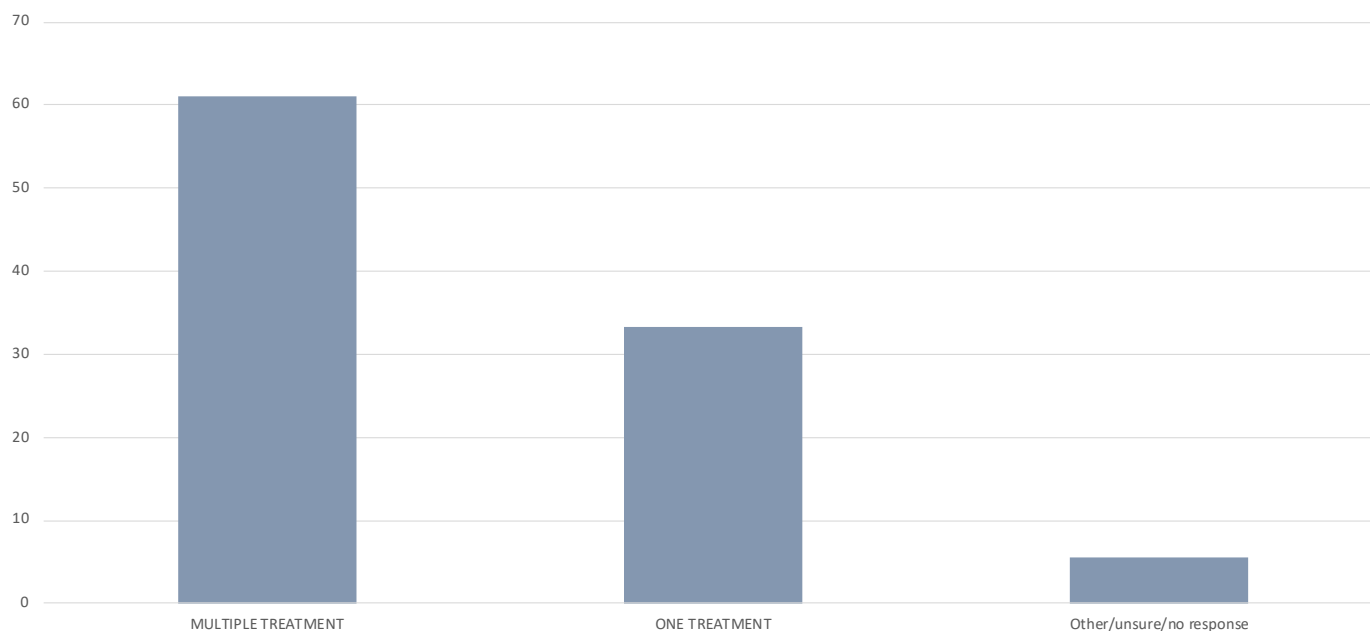


Figure 4.1: Conversations about treatment

Conversations about treatment: Participation in discussions

Of the participants who were presented with multiple options six (33.33%) described being told what to do without discussion, and four (22.22%) participated in the decision-making process.

Participant describes being presented with multiple options: They were told what to do without discussion

In the hospital, because I still don't know what was going on, I knew I was on a heavy steroid infusion. IV methyl pred. The neurologist saying that once I'm discharged from hospital, I will probably need infusions and could also need to take oral prednisolone. That was all that was given to me. I wouldn't call an option as such because I know nothing about it and she basically told me, "Yes, this is what you'll do. This is what you'll do. Participant NMO_001.

I think they're very minimal. He told me, within the first few days, that he was certain that it was neuromyelitis, that he was going to try and treat with steroids first to see if it made any change, and there'd been no difference. That's when he told me about the plasmapheresis, but I was never told about what to expect or what was happening or anything like that. I was just moved down to ICU, and next minute, I was having some lines put in my neck and just things like that. Then I had the pipe

put in. It was quite confronting. I didn't know what to expect. Participant NMO_011

Participant describes being presented with multiple options: Participated in the decision-making process

They gave me an MS nurse rather than the neurologist. She rang me and I think it was Eculizumab and sent me a whole lot of paperwork about the Rituximab, the Eculizumab and wanted me to take both, because, apparently, they go hand in hand. I was a bit reluctant at first. I didn't start treatment till February, but I needed to do my research and look at what were the side effects. The MS nurse that I had, her mum had been on Rituximab for arthritis. She said, "My mum has been on it for 10 years. She's doing well, she hasn't had any side effects." That was a bit reassuring because I thought, "Well, you're allowing your mum and you're a nurse." But I did notice that it was monoclonal... Then the other one, the Eculizumab, that was chemo. I thought, "Well, I don't want to have chemo treatment because I haven't got cancer," but I knew I needed something. I said, "Look, I'll accept the Rituximab and the Rituximab only." Because the risk was too great of having a relapse and losing my sight. Participant NMO_015

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

Table 4.3: Conversations about treatment: Participation in discussions

Conversations about treatment: Participation in discussions	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	2	22.22	4	44.44	4	50.00	2	20.00	3	33.33	3	33.33
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	3	33.33	1	11.11

Conversations about treatment: Participation in discussions	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	3	30.00	3	37.50	2	33.33	4	33.33	2	28.57	4	36.36
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	2	28.57	2	18.18

Conversations about treatment: Participation in discussions	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	3	37.50	9	34.62	4	40.00	5	31.25	1	50.00	2	66.67	4	26.67
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	4	50.00	8	30.77	3	30.00	4	25.00	0	0.00	0	0.00	4	26.67

Table 4.4: Conversations about treatment: Participation in discussions (Subgroup variations)

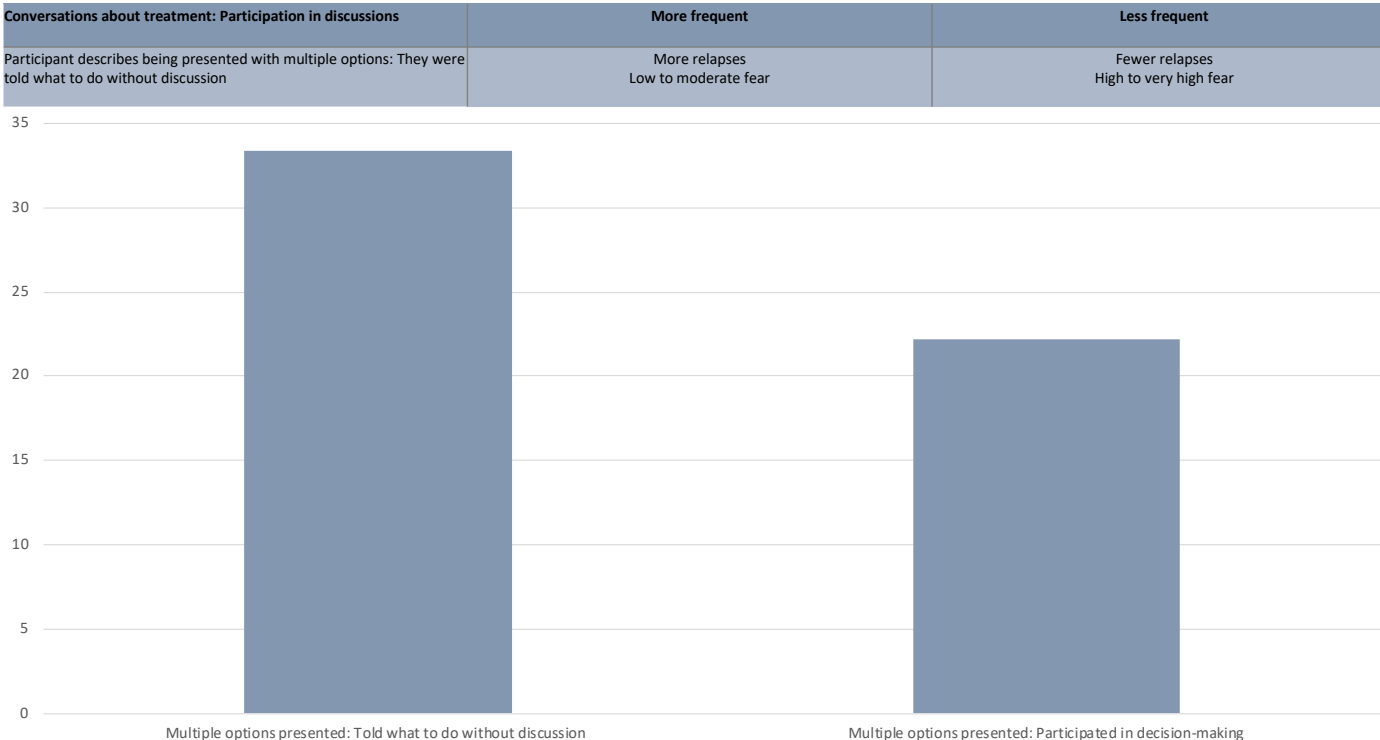


Figure 4.2: Conversations about treatment: Participation in discussions

Conversations about treatment: Specific treatments discussed

Some participants described specific treatments that were discussed, the most common was rituximab (n=11, 61.11%), followed by steroids (n=7, 38.89%), and plasma exchange (n=5, 27.78%).

Participant describes being presented with the option of rituximab

After the second I went, that's when they put me on Rituximab and really, that's the only thing apart from my vitamin D3/B12 that I have. Participant NMO_012

In 2010 I started on Rituximab. I was also on Azathioprine and Prednisone. Azathioprine I think was a half a tablet or one tablet 50mg I think, and Prednisone was dropped down to 1mg a day and then I would get a Rituximab infusion. Every time my B cells returned I'd get another infusion which was usually around 1.8 years. Participant NMO_002

They gave me an MS nurse rather than the neurologist. She rang me and I think it was Eculizumab and sent me a whole lot of paperwork about the Rituximab, the Eculizumab and wanted me to take both, because, apparently, they go hand in hand. I was a bit reluctant at first. I didn't start treatment till February, but I needed to do my research and look at what were the side effects. Participant NMO_015

Participant describes being presented with the option of steroids

Well, they basically told us that he needed to be admitted into hospital and he needed to be on high dose steroids. Participant NMOCA_007

The steroids and then when it happened again, seven months later, boom back on the IV steroids. Participant NMO_012

Yes. They, obviously, had started the steroids and the plasma exchange before diagnosing him with NMO. They believed it was an autoimmune disease they were just looking into, or they weren't certain on which one it was yet. They explained their treatment for most autoimmune diseases would be the plasma exchange and the steroids. Once they diagnosed him with the NMO they explained that Rituximab would deplete his B cells, so they started it that day. Participant NMOCA_002

Participant describes being presented with the option of plasma exchange

I've been on plasma exchanges and Rituximab and Methotrexate. Participant NMO_007

The steroids and then when it happened again, seven months later, boom back on the IV steroids. [chuckles] Then they gave me plasma exchange. Participant NMO_012

Yes. They, obviously, had started the steroids and the plasma exchange before diagnosing him with NMO. They believed it was an autoimmune disease they were just looking into, or they weren't certain on which one it was yet. They explained their treatment for most autoimmune diseases would be the plasma exchange and the steroids. Once they diagnosed him with the NMO they explained that Rituximab would deplete his B cells, so they started it that day. They have said that it's, obviously, early days for us. NAME PERSON CARED FOR is most likely to continue having Rituximab throughout his life in order to prevent relapses. Participant NMOCA_002

Table 4.5: Conversations about treatment: Specific treatment discussed

Conversations about treatment: Specific treatment discussed	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with the option of rituximab	11	61.11	5	55.56	6	66.67	5	62.50	6	60.00	4	44.44	7	77.78
Participant describes being presented with the option of steroids	7	38.89	4	44.44	3	33.33	4	50.00	3	30.00	4	44.44	3	33.33
Participant describes being presented with the option of plasma exchange	5	27.78	1	11.11	4	44.44	1	12.50	4	40.00	4	44.44	1	11.11

Conversations about treatment: Specific treatment discussed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with the option of rituximab	11	61.11	6	60.00	5	62.50	3	50.00	8	66.67	3	42.86	8	72.73
Participant describes being presented with the option of steroids	7	38.89	4	40.00	3	37.50	2	33.33	5	41.67	2	28.57	5	45.45
Participant describes being presented with the option of plasma exchange	5	27.78	5	50.00	0	0.00	2	33.33	3	25.00	1	14.29	4	36.36

Conversations about treatment: Specific treatment discussed	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being presented with the option of rituximab	11	61.11	3	37.50	14	53.85	2	20.00	10	62.50	1	50.00	1	33.33	10	66.67
Participant describes being presented with the option of steroids	7	38.89	4	50.00	11	42.31	7	70.00	7	43.75	0	0.00	2	66.67	5	33.33
Participant describes being presented with the option of plasma exchange	5	27.78	1	12.50	6	23.08	3	30.00	4	25.00	1	50.00	2	66.67	3	20.00

Table 4.6: Conversations about treatment: Specific treatment discussed

Conversations about treatment: Specific treatment discussed	More frequent	Less frequent
Participant describes being presented with the option of rituximab	Good to very good physical function Aged 45 or older	Moderate to very poor physical function Mid to low socioeconomic status Aged 18 to 44
Participant describes being presented with the option of steroids	Low to moderate fear	Aged 18 to 44
Participant describes being presented with the option of plasma exchange	More relapses High to very high fear Moderate to very poor physical function Trade or high school	Low to moderate fear Good to very good physical function University Aged 18 to 44

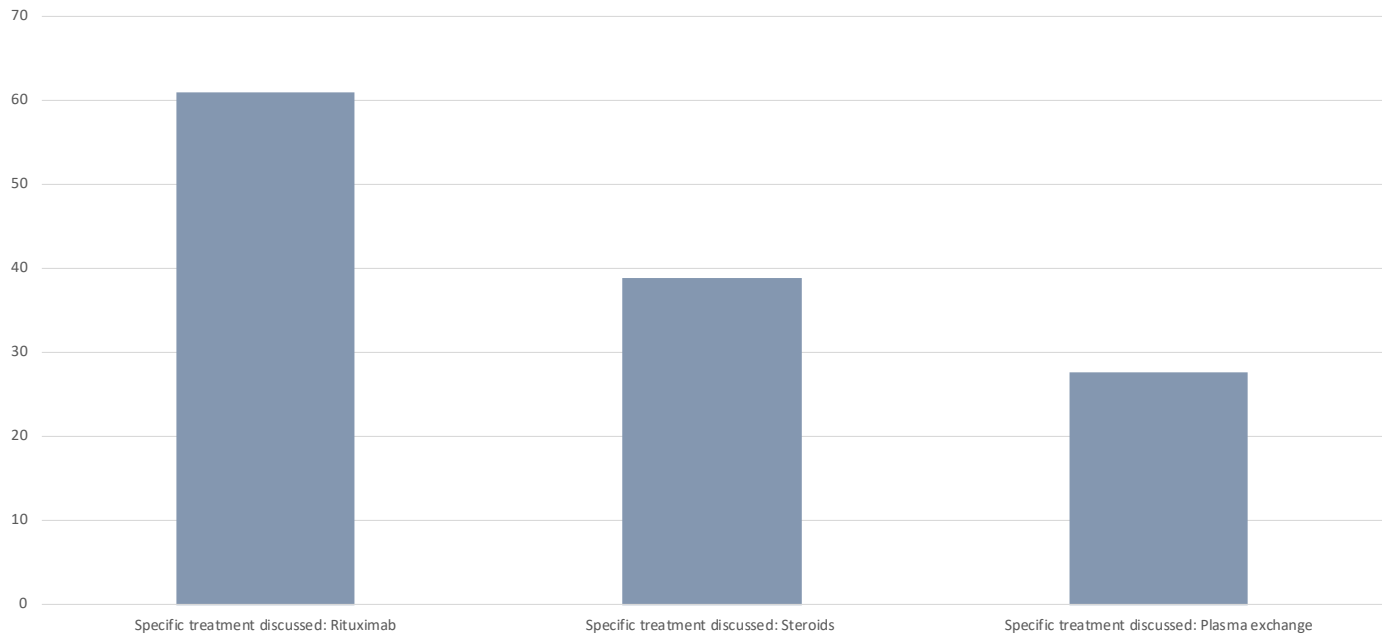


Figure 4.3: Conversations about treatment: Specific treatment discussed

Considerations when making decisions about treatment

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was Volume 3 (2020), Issue 4: PEEK Study in NMOSD

side effects as part of multiple aspects that they consider when making decisions about treatment, and this was described by five participants (27.78%).

Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment

I look at side effects and how they all affect me. Like how often I need to take something, for example. I just want to live my life the most normal as I can. I don't want to be taking pills three times a day. Participant NMO_005

I look at the side effects of treatment. I look at research, I look at, obviously, other people on Facebook and what they've had. Participant NMO_015

The side effects, how effective the medication, and then the side effect of the medication. Participant NMO_001

Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment

I think really the main thing is the effectiveness of it and whether or not that person understands your condition and is supportive of you. Participant NMO_004

The side effects, how effective the medication, and then the side effect of the medication. Participant NMO_001

Probably long term, and it is working at the moment, knowing that it is holding. If I didn't have my Rituximab, or if I get sick with the NMO, it strikes quite fast. Virtually what is probably in the mind. I know that the Rituximab that I'm having or plasma is a way of helping me type thing. Participant NMO_013

Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment

Oh, cost. Cost would be one of the things, that's because I no longer work. Participant NMO_011

Oh, cost is definitely a huge part of it. If the PBS didn't exist I would not be getting treatment. Participant NMO_014

Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment

I put all my trust in NAME DOCTOR because so far he's kept me going. He's got me out of trouble a few times, like when I've had an attack and I'm on my way to the hospital, when I get there he's waiting there for me. Participant NMO_007

Pretty much I was told I didn't have a decision to make because that was my only option. I did look into it and it seems to be the most popular one that people use for NMO, so I was quite comfortable with that. Participant NMO_008

I don't think I really make the decisions, I rely on my neurologist to make the decisions. Participant NMO_006

Participant describes taking the long-term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment

How it affects him. That is the main thing. In the long term and also in the short term and whether it affects his everyday ability to do his work because he is still obviously working. That's probably the main concern but it doesn't affect him adversely. Participant NMOCA_003

When I say side effects, I mean long-term issues, whether anything long-term would impact on his health. My work situation, because he's dependent on me. I have to try and juggle things around my work situation to get him to treatment. I guess that's really it. Participant NMOCA_007

Side effects, strictly long-term side effects. I understand that I'm to be immunosuppressed but what it's opening me up to. Participant NMO_014

Participant describes weighing up the benefits versus the risks as part of multiple considerations

I look at the side effects of treatment. I look at research, I look at, obviously, other people on Facebook and what they've had. I guess I gauge it on me because I know myself better than anyone and I look at what's going to be beneficial for my well-being. Participant NMO_015

Table 4.7 Considerations when making decisions about treatment

Considerations when making decisions about treatment	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function			
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%		
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	3	33.33	2	22.22	4	50.00	1	10.00	2	22.22	3	33.33		
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	33.33	1	11.11	2	25.00	2	20.00	3	33.33	1	11.11		
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22		
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	0	0.00	3	33.33	0	0.00	3	30.00	2	22.22	1	11.11		
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	2	22.22	0	0.00	1	12.50	1	10.00	1	11.11	1	11.11		
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	2	22.22	0	0.00	1	12.50	1	10.00	0	0.00	2	22.22		
Considerations when making decisions about treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older			
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%		
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	1	10.00	4	50.00	2	33.33	3	25.00	2	28.57	3	27.27		
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	1	14.29	3	27.27		
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	30.00	1	12.50	3	50.00	1	8.33	1	14.29	3	27.27		
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	3	30.00	0	0.00	0	0.00	3	25.00	1	14.29	2	18.18		
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	0.00	2	18.18		
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	1	10.00	1	12.50	2	33.33	0	0.00	0	0.00	2	18.18		
Considerations when making decisions about treatment	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	6	75.00	11	42.31	3	30.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	37.50	7	26.92	3	30.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	25.00	6	23.08	0	0.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	1	12.50	4	15.38	1	10.00	2	12.50	1	50.00	0	0.00	3	20.00
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	1	12.50	3	11.54	3	30.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	3	37.50	5	19.23	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 4.8: Considerations when making decisions about treatment (Subgroup variations)

Considerations when making decisions about treatment	More frequent	Less frequent
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	Low to moderate fear University	High to very high fear Trade or high school

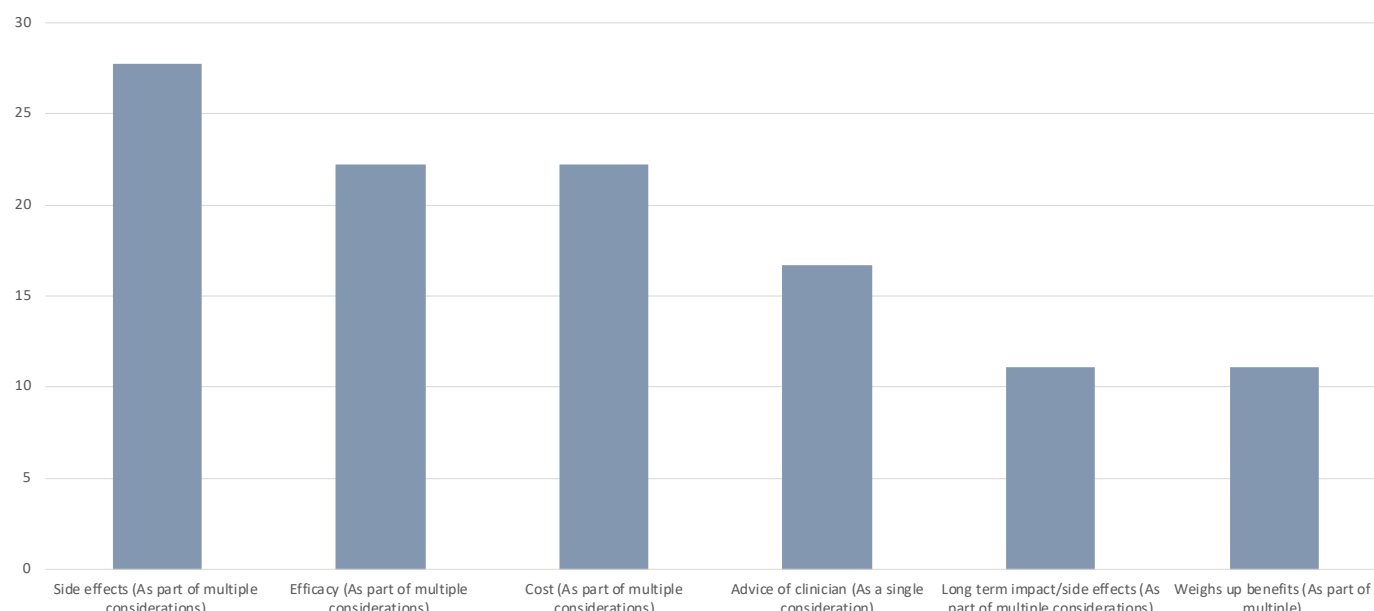


Figure 4.4 Considerations when making decisions about treatment

Decision-making over time

Participants 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 (total)

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 (total)

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

In the same way. Participant NMOCA_002

The same way. Participant NMO_015

Table 4.9: Decision-making over time

Decision-making over time	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes decision-making changing over time (total)	16	88.89	7	77.78	9	100.00	8	100.00	8	80.00	8	88.89	8	88.89
Participant describes no change in decision-making over time (total)	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	0	0.00	1	11.11
Other/unsure/no response	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	1	11.11	0	0.00

Decision-making over time	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes decision-making changing over time (total)	16	88.89	10	100.00	6	75.00	5	83.33	11	91.67	7	100.00	9	81.82
Participant describes no change in decision-making over time (total)	1	5.56	0	0.00	1	12.50	1	16.67	0	0.00	0	0.00	1	9.09
Other/unsure/no response	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	0	0.00	0	0.00

Decision-making over time	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes decision-making changing over time (total)	16	88.89	4	50.00	20	76.92	4	40.00	14	87.50	2	100.00	3	100.00	13	86.67
Participant describes no change in decision-making over time (total)	1	5.56	4	50.00	5	19.23	5	50.00	1	6.25	0	0.00	0	0.00	1	6.67
Other/unsure/no response	1	5.56	0	0.00	1	3.85	1	10.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 4.10: Decision-making over time (Subgroup variations)

Decision-making over time	More frequent	Less frequent
Participant describes decision-making changing over time (total)	More relapses Low to moderate fear Trade or high school Aged 18 to 44	Fewer relapses University

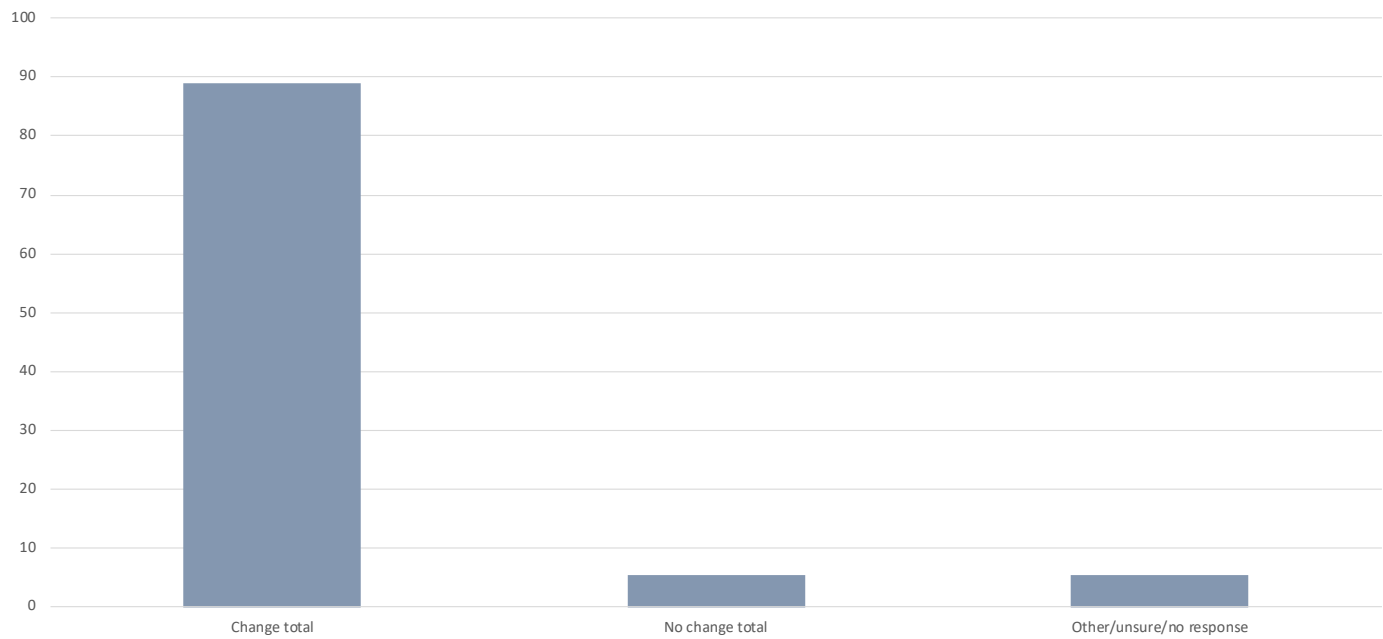


Figure 4.5: Decision-making over time

Decision-making over time

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

Participant describes decision-making changing over time as they are more informed and/or more assertive

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

Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations

My decision making has changed definitely. I always have multiple plans and ways out of things. Participant NMO_014

Yes, I've changed a lot in the way of what am I going to be able to do body-wise? Just day-to-day things. Participant NMO_012

I think we have changed the way we make decisions. This disease is really very much in your face, so that governs how you view things now, to the point where you're concerned about any relapses and so that has changed our lifestyle, I suppose. We're still fairly active but you're aware of this. Participant NMOCA_004

Participant describes no change in decision-making over time and there is no particular reason noted

Same way. I think we are quite too early in this journey to have made any other decisions in this. Participant NMOCA_003

The same way. Participant NMO_015

In the same way. Participant NMOCA_002

Table 4.11: Decision-making over time: Rationale for change

Rationale for change over time	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function			
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%		
Participant describes decision-making changing over time as they are more informed and/or more assertive	6	33.33	3	33.33	3	33.33	4	50.00	2	20.00	3	33.33	3	33.33		
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	1	11.11	2	22.22		
Rationale for change over time	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older			
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%		
Participant describes decision-making changing over time as they are more informed and/or more assertive	6	33.33	2	20.00	4	50.00	0	0.00	6	50.00	4	57.14	2	18.18		
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	3	30.00	0	0.00	3	50.00	0	0.00	0	0.00	3	27.27		
Rationale for change over time	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	6	33.33	3	37.50	9	34.62	1	10.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	2	66.67	1	6.67

Table 4.12: Decision-making over time: Rationale for change

Rationale for change over time	More frequent	Less frequent
Participant describes decision-making changing over time as they are more informed and/or more assertive	Low to moderate fear University Higher socioeconomic status Aged 18 to 44	High to very high fear Trade or high school Mid to low socioeconomic status Aged 45 or older

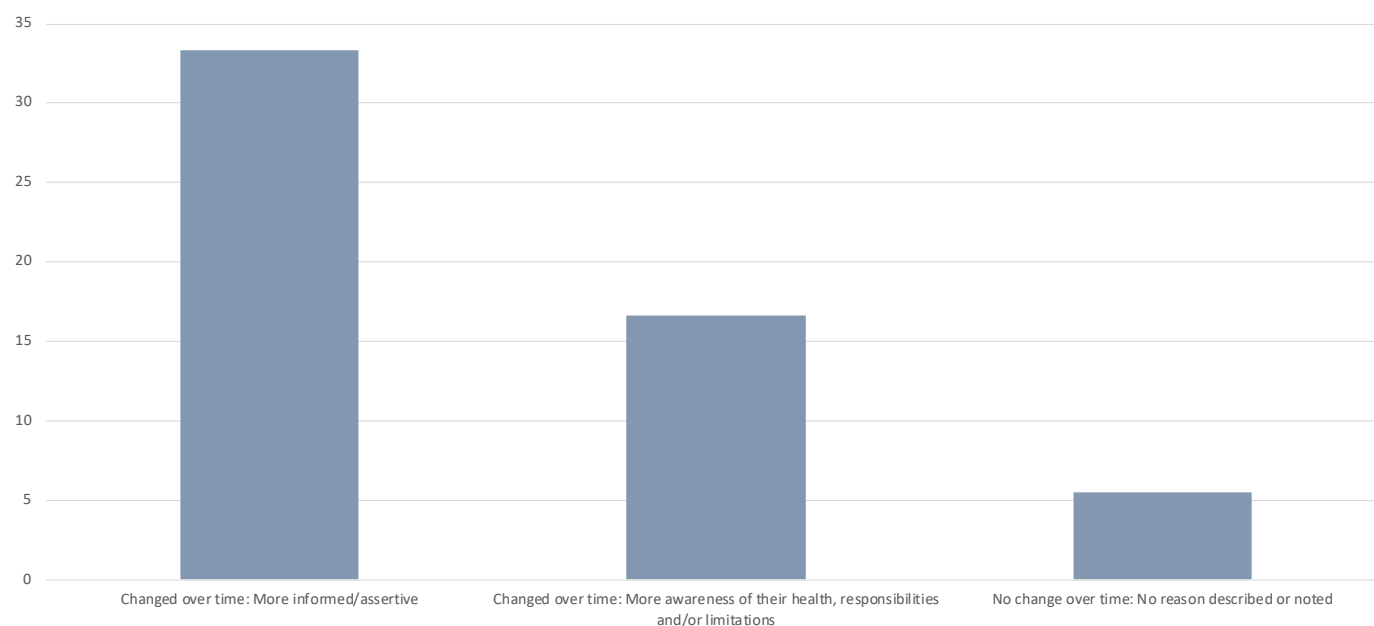


Figure 4.6: Decision-making over time: Rational for change and no change

Personal goals of treatment or care

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%).

Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition

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

Participants describe wanting to see physical improvements in their condition

The Valium does help relax my muscles at home and I go to physio once a week, but it's a very hard effort, it's getting worse type thing because my body's starting to, as I'm getting older, every other thing is virtually going type of thing. Participant NMO_013

Yes, I have. My neurologist and the physio collaborate together about what my treatment with him is. The physio has been the most help I've had out of anyone. When I was first diagnosed I was seeing him twice a week. We got to a stage where I was, apart from the pain, actually walking unaided. Still a bit wobbly, but it was working fine. Then after the relapse I went back with about 75%. Participant NMO_009

I was walking from - my husband dropped me off at the front door, to our ward. I work in a major hospital. That was enough to put me in a like I had to sit down. I was very focused on getting to a somewhat return of less disability. Being able to walk again. That was my main goal was I didn't want to be in a wheelchair. Participant NMO_017

Participant describes wanting to live independently

Yes. Absolutely. Well, NAME PERSON CARED FOR's whole goal is to get medical stability so that she can actually have a life. She's 23 now, she got sick at 13, and she literally hasn't had any social interaction,

any schooling education, nothing. She's just been literally sick. In and out of hospital, in and out of doctors' offices and therapy. The big goal is to find stability, is to be able to have a life. Participant NMO_016

I guess so. For me, it's more about now-- Because I've been quite stable the last six months, for me, it's been more about getting back my-- Because I'm very dependent now on people around me, I had to move back home, I don't drive. I stopped working, and I was in my last year of university, my second degree. Personally, everything now is about just getting my independence, like not being so dependent on others. I think because of this coronavirus situation in LOCATION METROPOLITAN now, we haven't really discussed anything for the last six months since I've been disabled. Participant NMO_005

The only goals that I have is that I'm registered through NDIS, so my goals are to be able to continue to live independently, and so I have support workers come in to help me. Participant NMO_011

Participant describes no personal goals of treatment or care (general)

No. Participant NMOCA_007

Not exactly. No. Participant NMO_008

No. Participant NMO_014

Participant describes wanting to reduce or not have medication

I don't like the side effects, long-term of mycophenolate with the increased chance of skin cancers and lymphoma. I think they're my concerns about being on it long term. I always have this fight with myself, internal dialogue going on. I also talk about it with my MS specialist, I have a fantastic relationship with him. He was invited to my conference as well. Every time I see him, I go, "I wish I could go off them." Participant NMO_004

Yes. I told them that I don't want anything anymore that's going to give me horrible side effects and they've been really good with that. I no longer take rituximab after pulling a nail and tooth thing. I can't do it. It's giving me a flare. I had very severe side effects from rituximab. They changed me to IVIG. That's a goal. That's to be on treatment and not really go through that many side effects, but at the end of the day, my actual goal is not to be on treatment anymore. Participant MOG_006

I started on a new drug that has a protocol that you have to have the infusion every six months. I really would like to move to only when my B cells return again like I was doing on the other drugs. Just lessened drug intake as much as I can. That would do. Participant NMO_002

Table 4.13: Personal goals of treatment or care

Personal goals of treatment or care	N MOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	2	22.22	5	55.56	2	25.00	5	50.00	5	55.56	2	22.22
Participants describe wanting to see physical improvements in their condition	3	16.67	3	33.33	0	0.00	1	12.50	2	20.00	2	22.22	1	11.11
Participant describes wanting to live independently	3	16.67	0	0.00	3	33.33	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes no personal goals of treatment or care (general)	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	0	0.00	3	33.33
Participant describes wanting to reduce or not have medication	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	1	11.11	1	11.11

Personal goals of treatment or care	N MOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	6	60.00	1	12.50	2	33.33	5	41.67	2	28.57	5	45.45
Participants describe wanting to see physical improvements in their condition	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27
Participant describes wanting to live independently	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	2	28.57	1	9.09
Participant describes no personal goals of treatment or care (general)	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	0	0.00	3	27.27
Participant describes wanting to reduce or not have medication	2	11.11	0	0.00	2	25.00	0	0.00	2	16.67	1	14.29	1	9.09

Personal goals of treatment or care	N MOSD		MOG		N MOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	1	12.50	8	30.77	2	20.00	6	37.50	1	50.00	2	66.67	5	33.33
Participants describe wanting to see physical improvements in their condition	3	16.67	2	25.00	5	19.23	2	20.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes wanting to live independently	3	16.67	2	25.00	5	19.23	0	0.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes no personal goals of treatment or care (general)	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes wanting to reduce or not have medication	2	11.11	2	25.00	4	15.38	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 4.14: Personal goals of treatment or care (Subgroup variations)

Personal goals of treatment or care	More frequent	Less frequent
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	More relapses High to very high fear Moderate to very poor physical function Trade or high school Aged 45 or older	Fewer relapses Low to moderate fear Good to very good physical function University Aged 18 to 44

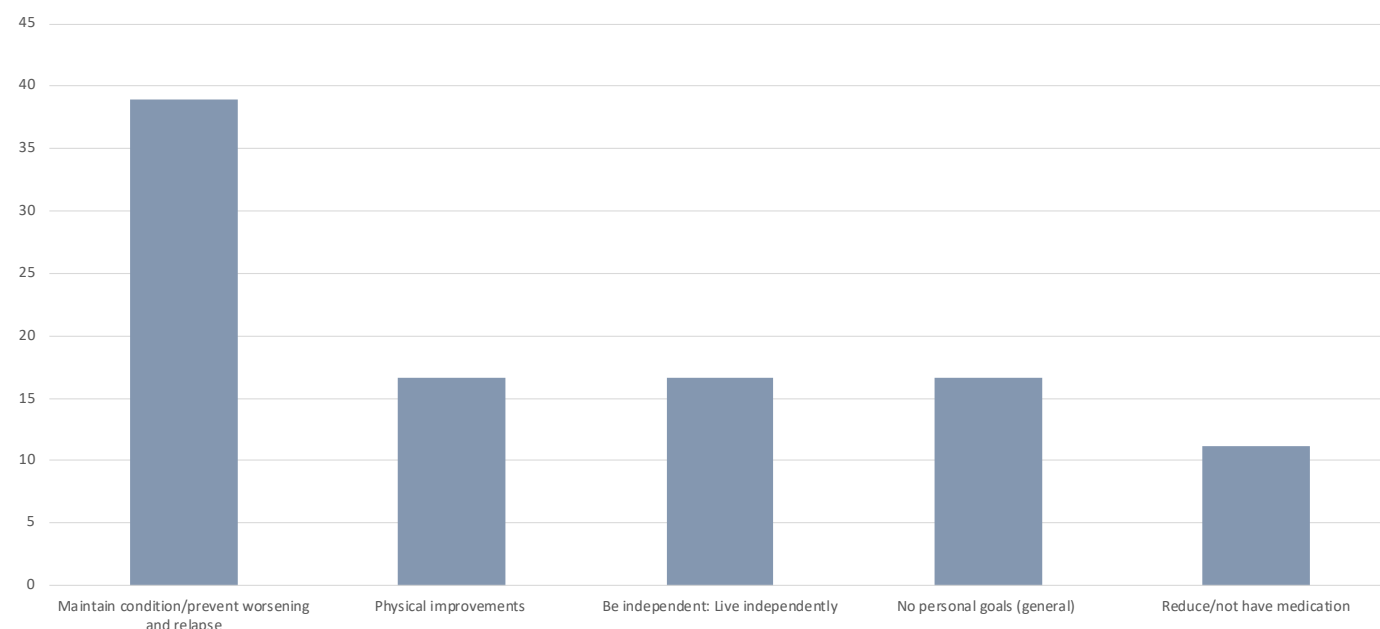


Figure 4.7: Personal goals of treatment or care