

## **Section 10**

### **Advice to others in the future: The benefit of hindsight**

### **Wish they had known earlier**

In the structured interview, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6, 33.33%).

### **Would this have influenced your decisions**

Participants were asked the follow-up question “would this have influenced your decisions,” the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

### **Aspect of treatment or care they would change**

In the structured interview, participants were asked if there was anything about their treatment or care they would change. The most common response from six participants (33.33%) was that they would not change any aspect of their care or treatment as they were satisfied with care and treatment received.

## Wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6, 33.33%).

**Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)**

*I suppose everything I know now, I wish I'd have known earlier. Probably the very first time-- When I got the phone call of NMO, it would have been good if that doctor could have pointed me in a direction of some particular information rather than me-- Or even when they first sent the blood tests, and sent me for the blood test. If there was somewhere or some information he could have sent me to, instead of me having to go through the minefield of everything in the world, rather than-- Just so that there was a basic grounding of NMO rather than it being this humongous thing that some people do die of, and some people get vomiting, and some people get choking, and you're like, "What?" Just a basic information would have been good when you first get told NMO. Participant NMO\_006*

*Yes, it was pretty grim. When I was diagnosed, they really didn't know very much. The statistics were really bad. The prognosis was particularly bad. In a way, I just thought, "Well, things are going to turn to shit in the next few years. Maybe don't bother doing-- It's just not going to be good," but that wasn't the case at all. I'm doing really well. Probably if I had a realistic picture from the beginning, it would have been better. Participant NMO\_010*

*Definitely. I wish I had have known that this disease was actually what it was at the initial diagnosis. Participant NMOCA\_007*

**Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration**

*Yes, definitely. I definitely would have read more after my first diagnosis online to find out that, "Hey, there are people who do regular infusion treatment, just to prevent from relapse." which I didn't know. Even though at six months, when I did the blood test, I was by then, I was like, "It's six months already, how come I'm not getting an infusion? and I asked the doctor. The doctor goes, "Oh, your antibody cell's not up yet." By the time it was nine months, I already had my relapse. I would have pushed if I'd heard more and more people say they do regular top-ups regardless. I would have pushed for my neurologist to probably give it to me. Then maybe my relapse will be avoided, I don't know. It's hard to tell but I would have pushed, yes. Participant NMO\_001*

*The only thing I think would have been the very first time when I went to the hospital and they sent me away. If I had have known about plasma pheresis. I had the steroids when I went back, but if I had have known about plasma pheresis, I would have asked for it sooner and I think it would have saved my eyesight because that's what did save my eyesight. I would have had both eyes I think, if it hadn't have been left for as long as it did. At the same time, I know there's so many things you can't just go in. It's very difficult. I get that, too. Participant NMO\_011*  
*Probably to take IVIG the first go. Participant NMOCA\_005*

**Participant describes wishing they had known to ask more questions and advocate for themselves more**

*100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness, I think. Participant NMO\_005*

*Yes, and also when I got the infection, I would have pushed harder to force someone to listen to me and I probably should have called in NAME's Rule because I knew I was sick, but I started to doubt myself. I started losing my confidence and I should have called, because I knew. My background is in PROFESSION and I've always worked in hospitals and stuff like that. I knew that something was wrong and I should have pushed it. Participant NMO\_011*

*Yes. When it first all happened, I wasn't probably strong enough now that this has happened to me to push more and find out. Yes, it's quite hard because if I would have known what I know now, I could have gone to the doctor and said, "Oh, look, I know that I'm a CD19 CD20. A lot of people don't even know what CD19 and CD20 is. Virtually, yes.*

*The levels of what's happening, they tell you it's MS, and it's not MS. I had different things. They opened up my spine, which I wish they didn't. I think they've done damage that way. If I would have known what I know now to when it first happened, I probably wouldn't. I would have been in a different situation. Participant NMO\_013*

**Table 10.1: Wish they had known earlier**

Wish they'd known earlier	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 wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	4	44.44	2	22.22
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	3	33.33	3	33.33	4	50.00	2	20.00	3	33.33	3	33.33
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	3	33.33	1	11.11

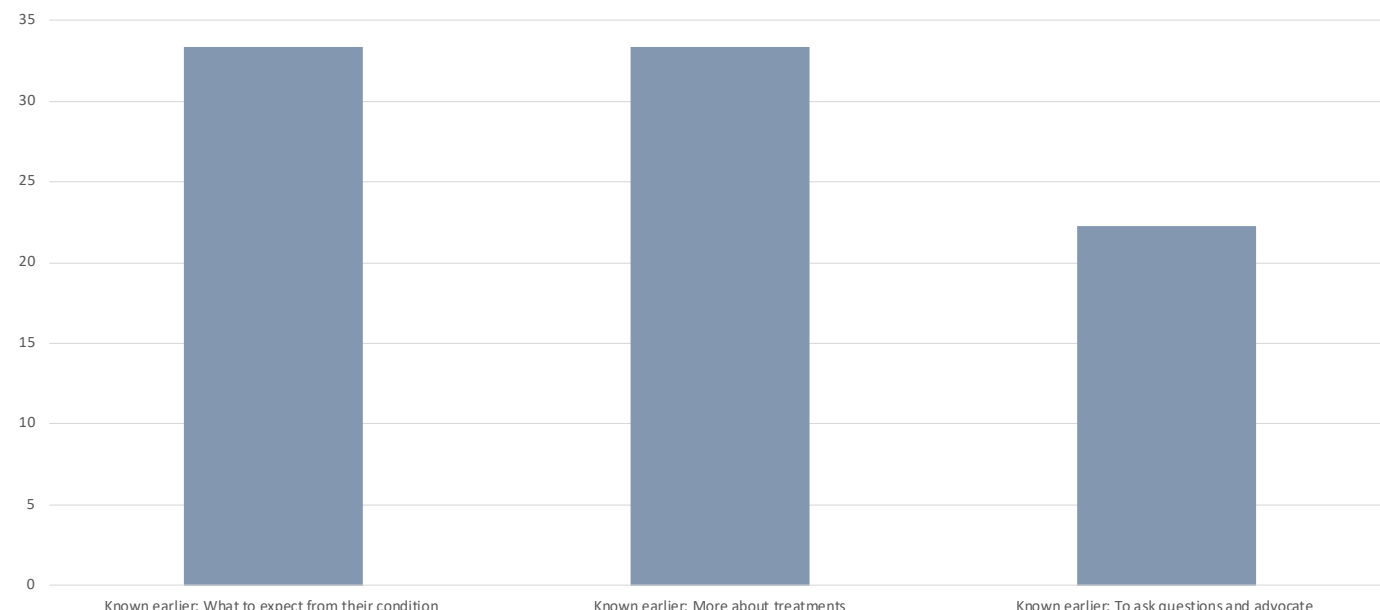
Wish they'd known earlier	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	2	20.00	4	50.00	0	0.00	6	50.00	4	57.14	2	18.18
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	4	40.00	2	25.00	4	66.67	2	16.67	2	28.57	4	36.36
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	2	28.57	2	18.18

Wish they'd known earlier	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 wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	3	37.50	9	34.62	3	30.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	0	0.00	6	23.08	2	20.00	5	31.25	1	50.00	3	100.00	3	20.00
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	1	12.50	5	19.23	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00

**Table 10.2: Wish they had known earlier (Subgroup variations)**

Wish they'd known earlier	More frequent	Less frequent
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	Fewer relapses Low to moderate fear Moderate to very poor physical function University Higher socioeconomic status Aged 18 to 44	More relapses High to very high fear Good to very good physical function Trade or high school Mid to low socioeconomic status Aged 45 or older
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	Low to moderate fear Mid to low socioeconomic status	High to very high fear Higher socioeconomic status



**Figure 10.1: Wish they had known earlier**

## Would this have influenced your decisions

Participants were asked the follow-up question “would this have influenced your decisions,” the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

### Participant feels that this would have influenced their decisions

*100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness. Participant NMO\_005*

*Yes, if I had have known about-- not that if I hadn't have known about rehab because I knew rehab was there but what things would have made it easier in the beginning to avoid the weight gain and things like that. Participant NMO\_014*

*Definitely if we knew that she had a spinal cord injury it would have made a huge difference to*

*knowing what services to reach out to. Participant NMO\_016*

### Participant feels that this would not have influenced their decisions

*I don't think so. Because I was focused so much on MS because I thought that's what I had, it wasn't really that much of a change in, I guess, my physical outlook for the rest of my life. I kind of already knew that I'm going to go downhill, and I kind of knew that I'll degrade. I already knew all those things, so I don't think so. Participant NMO\_003*

*I do not think there's anything I could have that I know now. I think just supporting what I found out at the time of diagnosis and what little bit doctor specialist had told us, so I don't think it would change.. Participant NMOCA\_003*

*No, not really. Participant NMOCA\_006*

**Table 10.3: Would this have influenced your decisions**

Would this have influenced your decisions	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 feels that this would have influenced their decisions	8	44.44	4	44.44	4	44.44	3	37.50	5	50.00	4	44.44	4	44.44
Participant feels that this would not have influenced their decisions	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

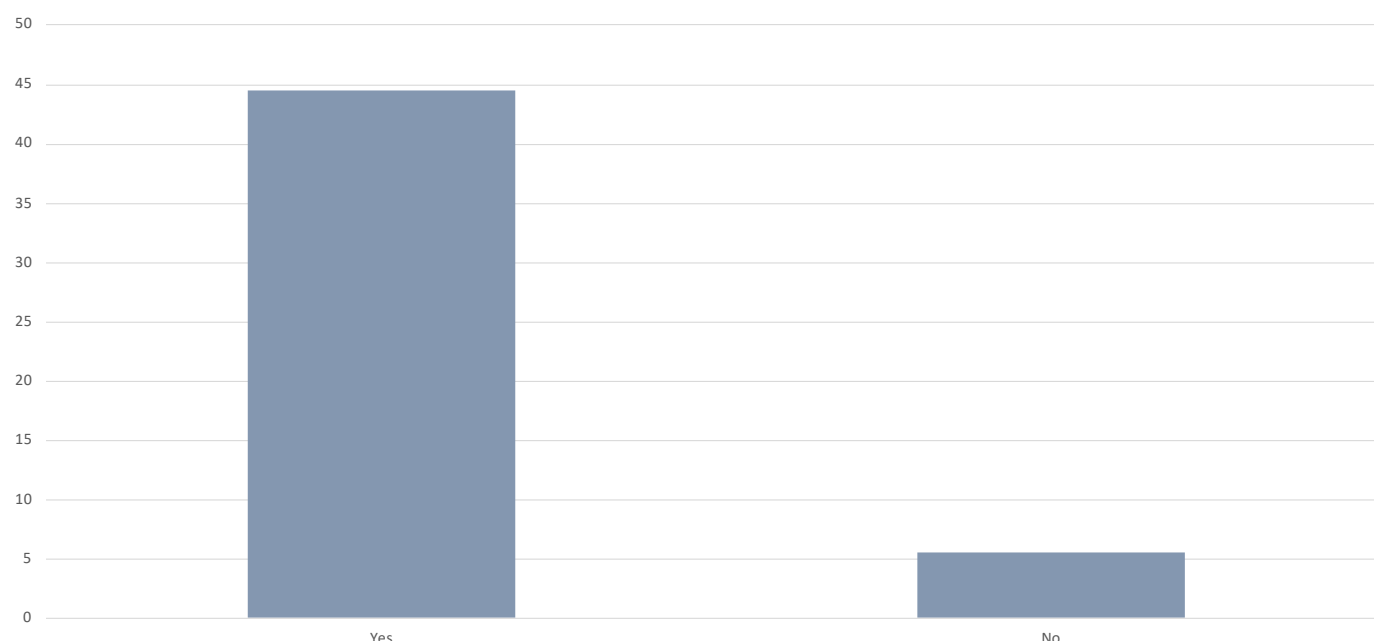
Would this have influenced your decisions	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant feels that this would have influenced their decisions	8	44.44	6	60.00	2	25.00	5	83.33	3	25.00	2	28.57	6	54.55
Participant feels that this would not have influenced their decisions	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	1	14.29	0	0.00

Would this have influenced your decisions	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 feels that this would have influenced their decisions	8	44.44	5	62.50	13	50.00	2	20.00	7	43.75	1	50.00	2	66.67	6	40.00
Participant feels that this would not have influenced their decisions	1	5.56	2	25.00	3	11.54	5	50.00	1	6.25	0	0.00	0	0.00	1	6.67

**Table 10.4: Would this have influenced your decisions (Subgroup variations)**

Would this have influenced your decisions	More frequent	Less frequent
Participant feels that this would have influenced their decisions	Trade or high school Mid to low socioeconomic status Aged 45 or older	University Higher socioeconomic status Aged 18 to 44



**Figure 10.2: Would this have influenced your decisions**

### Aspect of treatment or care they would change

In the structured interview, participants were asked if there was anything about their treatment or care they would change. The most common response from six participants (33.33%) was that they would not change any aspect of their care or treatment as they were satisfied with care and treatment received.

**Participant would not change any aspect of their care or treatment/satisfied with care and treatment received**

*I think I've been fortunate that I've had a really supportive neurologist that's head of the team and also a supportive GP. That's really all I can say. Participant NMO\_004*

*I don't think so, because I think they did the best that they possibly knew. It was just a matter of time before this horrible aquaporin-4, or whatever, popped out of and raised its head because it was negative three times before that. It's a bit of a process, really, but they did everything. I take my hat off to them for the knowledge that they know. Participant NMO\_012*

*At this stage right now, no. This is the first time since I've been sick where things are stable. I'm really happy with the doctors that trust me, and I love them. Participant NMO\_005*

**Participant describes wanting to have had better communication and/or continuity of care from health professionals**

*Yes, just have a more accessible point of contact, I think. Participant NMO\_003*

*Yes. That particular one of listening to the patient, that the patient needs to be listened to and needs to get taken on board. I would like to make sure that the doctors are listening properly and believing her. Participant NMO\_016*

**Participant would not change any aspect of their care or treatment (no reason given)**

*No, not really, no. Participant NMO\_007*

*No, nothing. Participant NMO\_009*

*No. Participant NMOCA\_002*

Table 10.5: Aspect of treatment or care they would change

Aspect of treatment or care they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	2	22.22	4	44.44
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	2	22.22	1	11.11
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	2	22.22	0	0.00

Aspect of treatment or care they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	3	30.00	3	37.50	2	33.33	4	33.33	1	28.57	5	45.45
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	3	42.86	0	0.00
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	0.00	2	18.18

Aspect of treatment or care they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	4	50.00	10	38.46	3	30.00	6	37.50	0	0.00	1	33.33	5	33.33
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	2	25.00	5	19.23	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	1	12.50	3	11.54	2	20.00	0	0.00	2	100.00	1	33.33	1	6.67

Table 10.6: Aspect of treatment or care they would change (Subgroup variations)

Aspect of treatment or care they would change	More frequent	Less frequent
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Fewer relapses Low to moderate fear Good to very good physical function Aged 45 or older	More relapses High to very high fear Moderate to very poor physical function

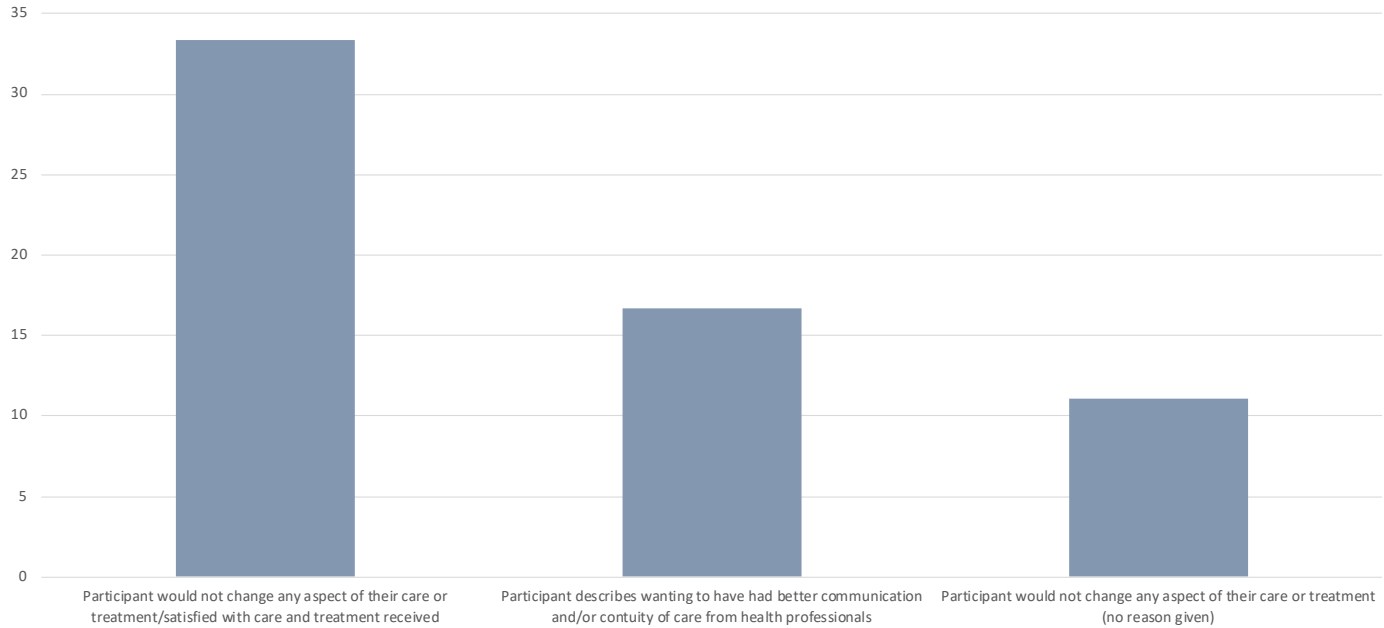


Figure 10.3: Aspect of treatment or care they would change