

Section 8

Quality of life

Section 8: Quality of life

Experience of quality of life

In the structured interview, 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%).

Impact on mental health

In the structured interview, participants were asked whether their mental health had been impacted. There were 15 participants (83.33%) who gave a description suggesting that overall, there was at least some impact on mental health.

Regular activities to maintain mental health

In the structured interview, 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%).

Regular activities to maintain health

In the structured interview, 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.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 12 participants (66.67%) that described a negative impact on relationships. Where participants described relationships being suffering, this was primarily in relation to their reduced capacity for socialising (n=6, 33.33%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 10 participants (55.56%) that felt there was an additional burden. Where participants felt there was an additional burden, this was primarily in relation to extra household duties and responsibilities that their family must take on (n=5, 27.78%), and needing extra assistance to get to appointments (n=5, 27.78%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 14 participants (77.78%) that gave a description suggesting that overall there was at least some cost burden. There were 10 participants (55.56%) that spoke about cost burden in relation to needing to take time off work and nine participants (50.00%) that reported cost burden in relation to the cost of treatments (including repeat scripts).

Overall impact of NMOSD on quality of life

In the online questionnaire, participants were asked to rate the overall impact of having a NMOSD or MOG on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is Life was great. The median impact of quality of life from NMOSD was 2.00 (IQR= 1.28), in the “life was distressing” range

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their condition. Overall, the average fear of progression score for NMOSD participants in this study indicated high levels of anxiety.

The responses to individual questions of the Fear of Progression questionnaire for participants with NMOSD showed that 50% or more participants that were often or very often worried about; disease progression (n=11, 61.11%), reaching professional or personal goals (n=12, 66.67%), relatives being diagnosed with disease (n=9, 50.00%), being able to pursue hobbies (n=15, 83.33%), treatment will damage body (n=11, 61.11%), worried about family if anything happens to them (n=11, 61.11%), and not being able to work (n=9, 50.00%).

Experience of quality of life

In the structured interview, 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%).

Participant describes an overall negative impact on quality of life

Sure. Pretty much I can't do the things as much, like the housework and all of those things. Looking after my son and enjoying time with him, but having said that, it's just the stress of it as well on the family. I have been sick for quite some time so it's been quite difficult in that regard. Participant NMO_008

Definitely. My quality of life is yes, desperately low, there's not a lot I can do, from a person who was fit, healthy, yes, I did everything and now I can't do 95% of the things I used to do. Participant NMO_009

My quality of life is that I have to now depend on everybody, where before I was very independent. Participant NMO_013

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics

It has because they're always, when we go anywhere, it's, "Be careful here. Be careful here. There's a bump on the footpath. Watch out you don't fall over." They're always like, "Am I all right?" To see that I haven't fallen over and things like that. Participant NMO_007

Sure. Pretty much I can't do the things as much, like the housework and all of those things. Looking after my son and enjoying time with him, but having said that, it's just the stress of it as well on the family. I have been sick for quite some time so it's been quite difficult in that regard. Participant NMO_008

Yes, absolutely. They don't just fully understand the disease. They were very upset when I first had it

and they found it difficult, so I spent a lot of the time trying to console them. A lot of my, including my family, they'll ask me out to places and that and so I can't always go, or I'm not able to do it and I am often saying I'm too tired. I think sometimes that they forget, so they can sometimes stop asking or including you to do things or they get a bit like, "Well yes, she's tired again," and not realise how much the disease can knock you around. Participant NMO_011

Participant describes negative impact on quality of life as a result of reduced capacity for physical activity

Yes. I guess when my partner met me, I was a very different person. I played a lot of high level sport, and that's how we met so going from that to being told that I should have looked at having children at 21 years old. Then obviously losing my job, my mental health was heavily affected, which I guess affected all my family relationships. My partner saw me go from this super-outgoing person who is very active and very optimistic to basically not really wanting to do anything because it could put me at risk and kind of like, what's the point if I'm just going to be in a wheelchair later on, so he had to really work hard to get me, I guess, out of that mindset. Participant NMO_003

My partner and my dad drove me wherever I needed to be. Nowadays- my relationship with some of my friends changed because of the things that we used to do together, I used to be big into mountain biking and stuff which I obviously can't do anymore. Some of those relationships have changed. I used to actively- playing a sport at a high level and then not playing sport at a high level is pretty upsetting. Participant NMO_010

Participant describes negative impact on quality of life due to reduced social interaction

Cancelling things, where maybe just catching up for a coffee or something like that, and then all of a sudden, then that morning, you feel like crap, and you have to cancel. I think I cancelled more than I actually go out. Participant NMO_012

Oh definitely, unfortunately. We've lost quite a few friends because I think we're not the fun couple anymore. The ones that would be the first in the pool and there at the start of the party and there at the end... We used to be fun but we're not as much

fun now. Sometimes we go to parties, we get there and after an hour, NAME PERSON CARED FOR will say, "I feel so bad I need to go home," so we go home. We're not the fun couple anymore. Participant NMOCA_005

Even quality of life like during COVID now, I haven't seen my friends since April. We talk but it's just that the face to face interaction, it sort of put up with, I don't really want to put myself out there and be exposed to COVID just in case, I don't go out as much. If I don't have this condition, I probably would go out like I would normally do and I probably wouldn't care that much. Participant NMO_001

Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future

My partner saw me go from this super-outgoing person who is very active and very optimistic to basically not really wanting to do anything because it could put me at risk and kind of like, what's the point if I'm just going to be in a wheelchair later on, so he had to really work hard to get me, I guess, out of that mindset. I see a psychologist and stuff like that to help me come to terms with it. I'm not as outgoing and stuff anymore because, obviously, I know there's repercussions for me now. Participant NMO_003

This is a mental thing that I still have to adapt to, and that some people think I still need to go and see a psychiatrist. Participant NMO_012

Yes. We have three kids who he hasn't seen in eight weeks. There's, obviously, a lot of fear there about whether he will get to see them grow up, and what disability he might have, and how that would

change the way he cares for our kids. Participant NMOCA_002

Participant describes negative impact on quality of life as a result of fatigue

Yes definitely. I feel more tired. I'm not as energetic as I used to be. I used to do everything in the house and I'm not tired. Nowadays I struggle to even go down to the shops and just walk a few shops. Participant NMO_001

I think definitely yes. With my family I guess just possibly feeling a little bit more fatigued than normal because of the loss of vision, psychologically possibly because of the effect of how you might look with one lazy eye. Participant NMO_002

With her quality of life, like I said, she has a lot of fatigue. She doesn't have much interest in anything. Participant NMOCA_006

Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability

Virtually, the quality of life that I used to play golf, tennis, where now, my quality of life feels-- I'm quite happy to stay at home and just go out on a weekend or something like that. I can't walk and run and do things like that. It's disappointing, but it happens. Participant NMO_013

We used to go on a lot of bush walks and stuff like that if we could, but she can't do that anymore. She can't walk. You can't have a walker in the bush. It's changed. We've sold the bikes, we've sold the kayaks, she sold her golf clubs. It was really hard because we're not going to do that anymore. Participant NMOCA_005

Table 8.1: Experience of quality of life

Impact on quality of life	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 negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	12	66.67	5	55.56	7	77.78	6	75.00	6	60.00	7	77.78	5	55.56
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	6	33.33	4	44.44	2	22.22	2	25.00	4	40.00	3	33.33	3	33.33
Participant describes negative impact on quality of life due to reduced social interaction	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	1	11.11	3	33.33
Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future	3	16.67	0	0.00	3	33.33	1	12.50	2	20.00	0	0.00	3	33.33
Participant describes negative impact on quality of life as a result of fatigue	3	16.67	1	11.11	2	22.22	3	37.50	0	0.00	2	22.22	1	11.11
Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	1	11.11	2	22.22
Participant describes an overall negative impact on quality of life	16	88.89	8	88.89	8	88.89	8	100.00	8	80.00	7	77.78	9	100.00

Impact on quality of life	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 negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	12	66.67	7	70.00	5	62.50	3	50.00	9	75.00	6	85.71	6	54.55
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	6	33.33	4	40.00	2	25.00	1	16.67	5	41.67	3	42.86	3	27.27
Participant describes negative impact on quality of life due to reduced social interaction	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	2	14.29	2	18.18
Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	2	28.57	1	9.09
Participant describes negative impact on quality of life as a result of fatigue	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	14.29	1	9.09
Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability	3	16.67	3	30.00	0	0.00	2	33.33	1	8.33	0	0.00	3	27.27
Participant describes an overall negative impact on quality of life	16	88.89	9	90.00	7	87.50	6	100.00	10	83.33	6	85.71	10	90.91

Impact on quality of life	More frequent	Less frequent
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	More relapses Moderate to very poor physical function Aged 18 to 44	Fewer relapses Good to very good physical function Mid to low socioeconomic status Aged 45 or older
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Fewer relapses	More relapses Mid to low socioeconomic status
Participant describes an overall negative impact on quality of life	Low to moderate fear Good to very good physical function Mid to low socioeconomic status	Moderate to very poor physical function

Table 8.2: Experience of quality of life (Subgroup variations)

Impact on quality of life	More frequent	Less frequent
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	More relapses Moderate to very poor physical function Aged 18 to 44	Fewer relapses Good to very good physical function Mid to low socioeconomic status Aged 45 or older
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Fewer relapses	More relapses Mid to low socioeconomic status
Participant describes an overall negative impact on quality of life	Low to moderate fear Good to very good physical function Mid to low socioeconomic status	Moderate to very poor physical function

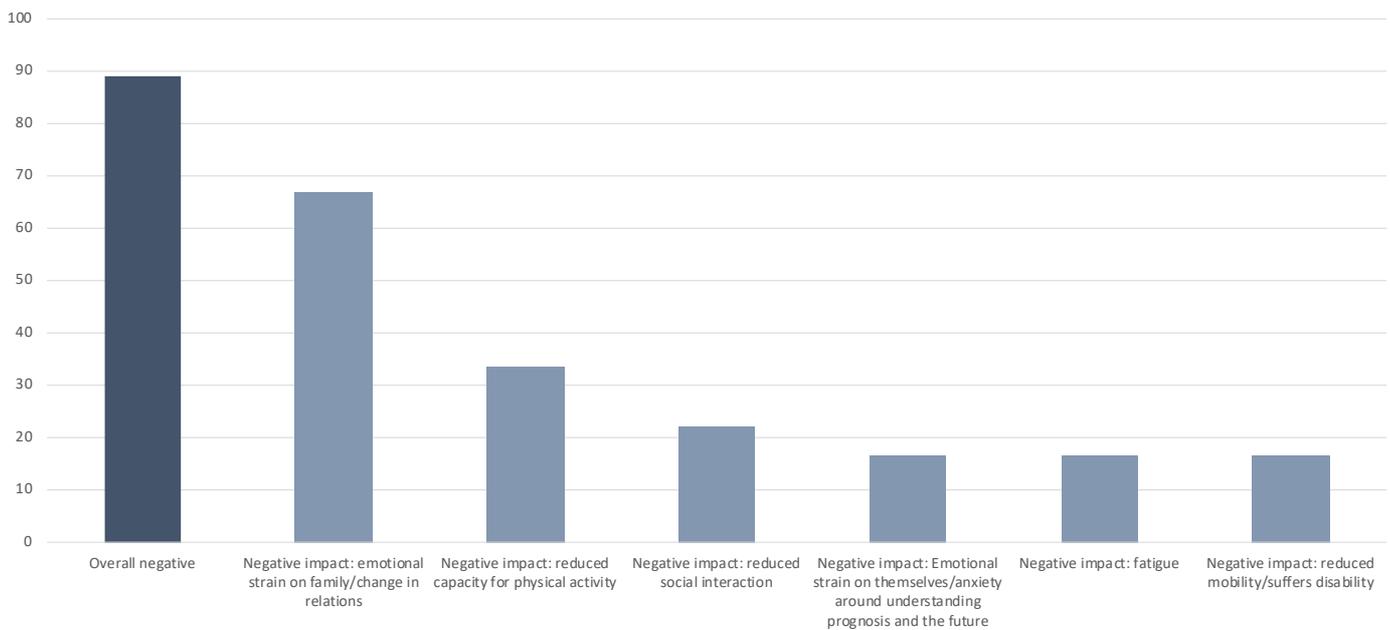


Figure 8.1: Experience of quality of life

Impact on mental health

In the structured interview, participants were asked whether their mental health had been impacted. There were 15 participants (83.33%) who gave a description suggesting that overall, there was at least some impact on mental health.

Participant gives a description suggesting that overall, there was at least some impact on mental health

I think it had a huge impact. Especially like I said due to the fact that one eye tends to move on its own sometimes and that is very mentally and psychologically draining. Also just maybe feel anxious all the time as well just because I just didn't deal with the visual system. Participant NMO_002
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. Participant NMO_010

It's quite depressing sometimes, especially when I get to the stage where it spasms up my whole body. I've got to lay on a bed and then my mind's telling me, "You got to get up. You got to get up. You can't lay in bed," type thing. Participant NMO_013

Participant gives a description suggesting that overall, there was no impact on mental health

I don't think it's affected either of us I don't know how it's changing if symptoms become more severe, but I think he's just taking it day by day and just trying to do the best we can, but so far we have been fine. Participant NMOCA_003

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

Table 8.3: Impact on mental health

Impact on mental health	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 gives a description suggesting that overall, there was at least some impact on mental health	15	83.33	7	77.78	8	88.89	7	87.50	8	80.00	7	77.78	8	88.89
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	11.11	0	0.00	1	12.50	0	0.00	0	0.00	1	11.11

Impact on mental health	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 gives a description suggesting that overall, there was at least some impact on mental health	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	7	100.00	8	72.73
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

Impact on mental health	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 gives a description suggesting that overall, there was at least some impact on mental health	15	83.33	6	75.00	21	80.77	4	40.00	14	87.50	1	50.00	3	100.00	12	80.00
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	12.50	2	7.69	4	40.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 8.4: Impact on mental health (Subgroup variations)

Impact on mental health	More frequent	Less frequent
Participant gives a description suggesting that overall, there was at least some impact on mental health	Aged 18 to 44	Aged 45 or older

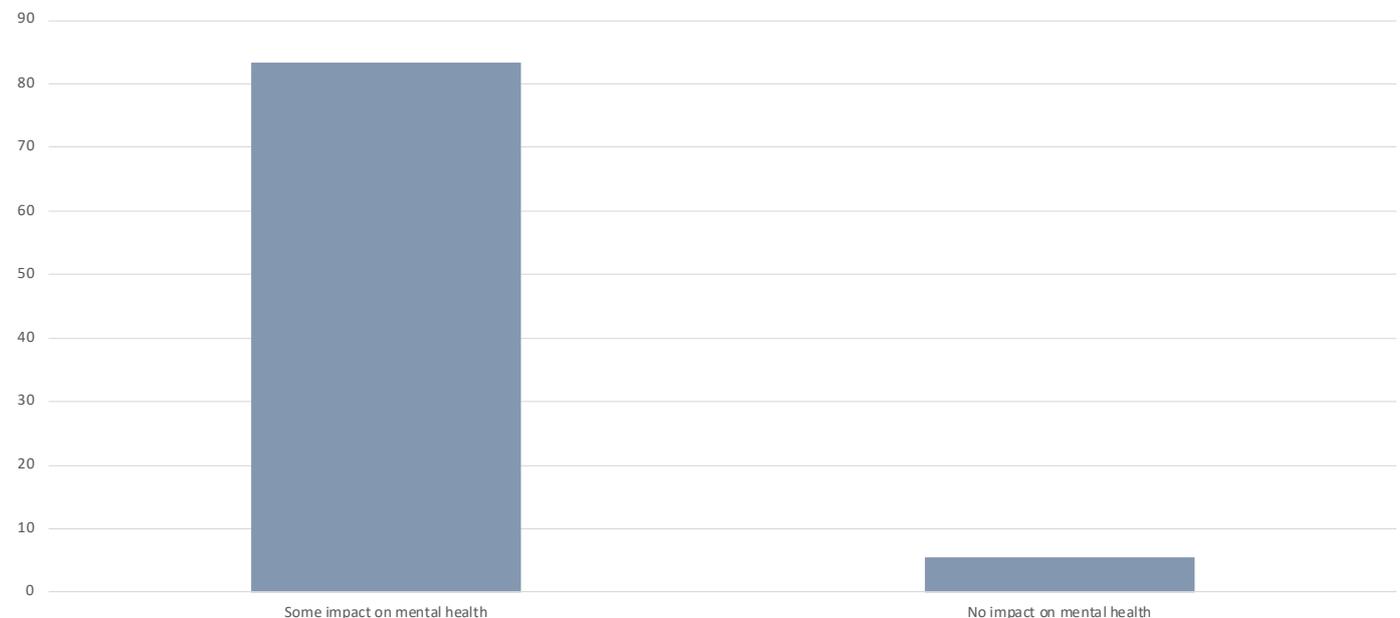


Figure 8.2: Impact on mental health

Regular activities to maintain mental health

In the structured interview, 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

Table 8.5: Regular activities to maintain mental health

Activities to maintain mental health	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 the importance of physical exercise	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	2	22.22	4	44.44
Participant describes using mindfulness and/or meditation	5	27.78	2	22.22	3	33.33	1	12.50	4	40.00	3	33.33	2	22.22
Participant describes consulting a mental health professional	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	1	11.11	2	22.22
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant describes no activities to maintain mental health	1	5.56	1	11.11	0	0.00	1	12.50	0	0.00	0	0.00	1	11.11

Activities to maintain mental health	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 the importance of physical exercise	6	33.33	1	10.00	5	62.50	1	16.67	5	41.67	3	42.86	3	27.27
Participant describes using mindfulness and/or meditation	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	3	14.29	2	18.18
Participant describes consulting a mental health professional	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes no activities to maintain mental health	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

Activities to maintain mental health	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 the importance of physical exercise	6	33.33	4	50.00	10	38.46	0	0.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes using mindfulness and/or meditation	5	27.78	2	25.00	7	26.92	0	0.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes consulting a mental health professional	4	22.22	1	12.50	5	19.23	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	2	25.00	5	19.23	1	10.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	2	25.00	4	15.38	2	20.00	1	6.25	1	50.00	1	33.33	1	6.67
Participant describes no activities to maintain mental health	1	5.56	1	12.50	2	7.69	3	30.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 8.6: Regular activities to maintain mental health (Subgroup variations)

Activities to maintain mental health	More frequent	Less frequent
Participant describes the importance of physical exercise	Fewer relapses Low to moderate fear Good to very good physical function University	More relapses High to very high fear Moderate to very poor physical function Trade or high school
Participant describes using mindfulness and/or meditation	High to very high fear	Mid to low socioeconomic status Low to moderate fear Aged 18 to 44

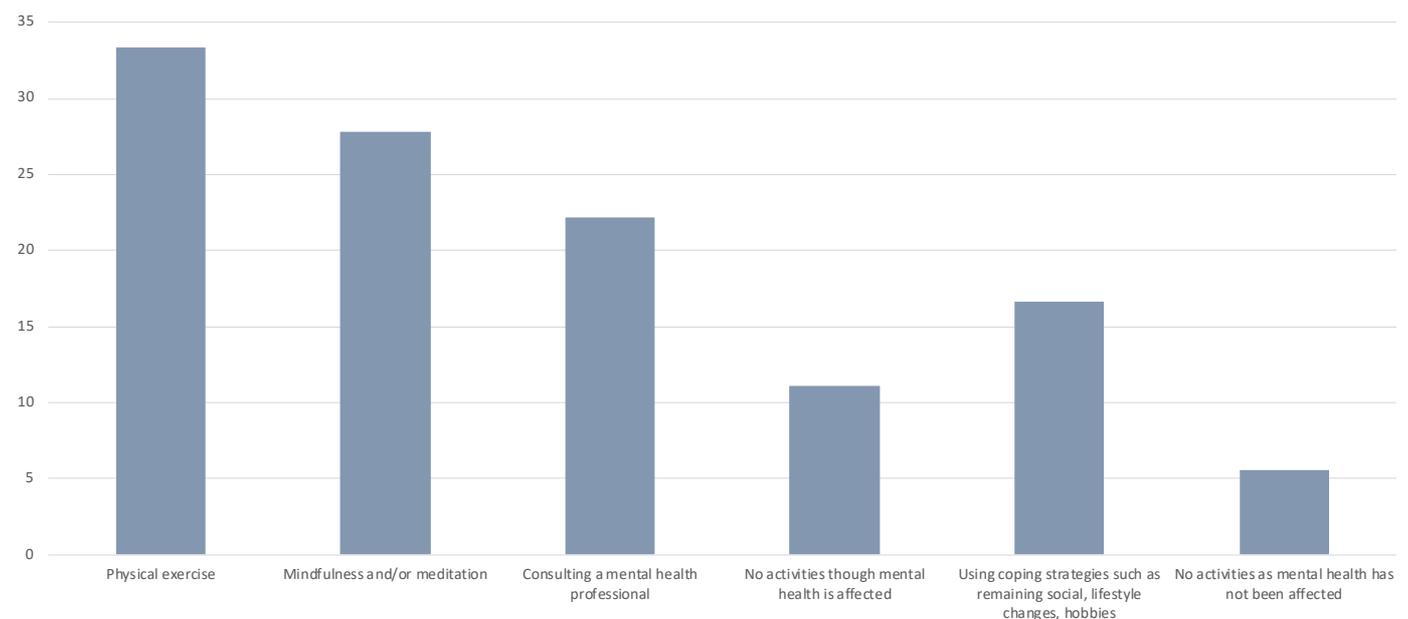


Figure 8.3: Regular activities to maintain mental health

Regular activities to maintain health

In the structured interview, 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.

In relation to subgroup variations, participants in the subgroups *Aged 45 or older* (27.27%), *Trade or high school* (20.00%), *Mid to low socioeconomic status* (16.67%), and *Family and carers* (10.00%) described staying physically active less frequently than the general NMOSD population (38.89%), while those in the subgroups *Low to moderate fear* (50.00%) *Aged 18 to 44* (57.14%), *University* (62.50%) and *Higher socioeconomic status* (50.00%) described this more frequently.

Participants in the subgroup *Mid to low socioeconomic status* (16.67%) described the importance of understanding their limitations less frequently than the general NMOSD population (33.33%).

Participants in the subgroup *Family and carers* (10.00%) describes the importance of self care less frequently than the general NMOSD population (27.78%).

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

Table 8.7: Regular activities to maintain health

Regular activities to maintain health	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 physically active	7	38.89	3	33.33	4	44.44	4	50.00	3	30.00	1	11.11	6	66.67
Participant describes the importance of understanding their limitations	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	3	33.33	3	33.33
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	3	33.33	2	22.22	3	37.50	2	20.00	1	11.11	4	44.44
Participant describes the importance of complying with treatment	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	2	22.22	1	11.11

Regular activities to maintain health	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 physically active	7	38.89	2	20.00	5	62.50	1	16.67	6	50.00	4	57.14	3	27.27
Participant describes the importance of understanding their limitations	6	33.33	4	40.00	2	25.00	1	16.67	5	41.67	2	28.57	4	36.36
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	1	28.57	4	36.36
Participant describes the importance of complying with treatment	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	2	28.57	1	9.09

Regular activities to maintain health	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 physically active	7	38.89	2	25.00	9	34.62	1	10.00	7	43.75	0	0.00	0	0.00	7	46.67
Participant describes the importance of understanding their limitations	6	33.33	4	50.00	10	38.46	4	40.00	6	37.50	0	0.00	1	33.33	5	33.33
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	4	50.00	9	34.62	1	10.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes the importance of complying with treatment	3	16.67	1	12.50	4	15.38	3	30.00	2	12.50	1	50.00	1	33.33	2	13.33

Table 8.8: Regular activities to maintain health (Subgroup variations)

Regular activities to maintain health	More frequent	Less frequent
Participant describes being physically active	Low to moderate fear Good to very good physical function University Higher socioeconomic status Aged 18 to 44	Moderate to very poor physical function Trade or high school Mid to low socioeconomic status Aged 45 or older
Participant describes the importance of understanding their limitations	-	Mid to low socioeconomic status
Participant describes the importance of self care e.g. more rest, support for housework etc.	Good to very good physical function	Moderate to very poor physical function

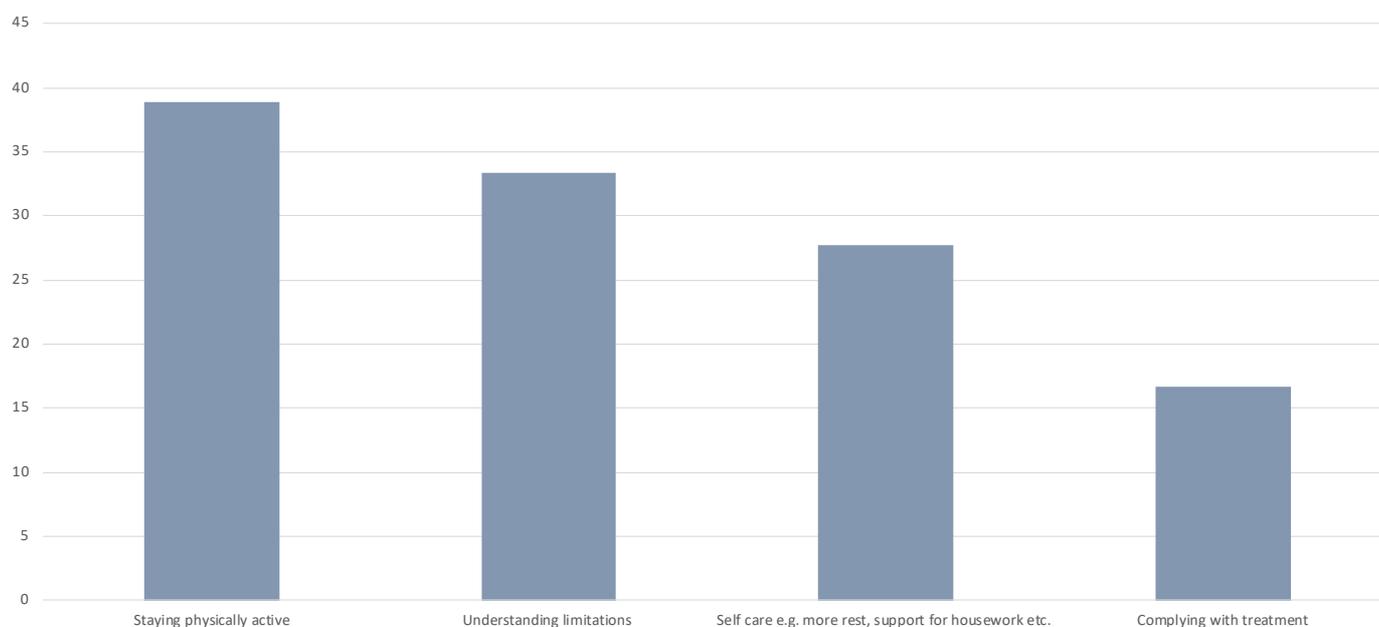


Figure 8.4: Regular activities to maintain health

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 12 participants (66.67%) that described a negative impact on relationships.

Participant describes a negative impact on relationships

Yes, definitely. I've lost friends over it because people don't understand it. I lost my husband. It definitely affects relationships and it's definitely affected the quality of my life. Participant NMO_004

That's why I don't see my friends that much. I haven't seen them since COVID and I don't even really see my extended family either because they live in LOCATION METROPOLITAN where the clusters are. Participant NMO_001

I think so. Some friends, they just don't want to hear. If you just need to get something off your chest, or whatever, that's something about you, what you're feeling, some people just go, "All right. Here she goes again." It's that brush off. Now, I pretty much don't say too much at all. Unless it's the real, real close friends, or my husband. Participant NMO_012

Participant describes no impact on relationships

No. Participant NMO_002

No. Participant NMO_015

No, not at all. My friends know and they're 100% supportive. They regularly ask, "How are things going? Participant MOG_007

Participant describes a positive impact on relationships

I've met new friends, which is amazing. Relationships, yes, I think the whole episode when it was initially first happening opened a lot of people to me. I think I've got better relationships and the ones that I do have now. Participant NMO_006

No. I think it's made it stronger. I think it's made me a stronger person, and I think it's made our relationships stronger, and I think you have a different outlook about life, and about any worries that were insignificant. I just let it go now, because it's not worth it. Participant NMO_017

I think more good than bad. Everybody has been very supportive including at his work. Participant NMOCA_003

Table 8.9: Impact on relationships

Impact on relationships	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 a negative impact on relationships	12	66.67	6	66.67	6	66.67	5	62.50	7	70.00	6	66.67	6	66.67
Participant describes no impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	0	0.00	2	22.22
Participant describes a positive impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11

Impact on relationships	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 a negative impact on relationships	12	66.67	8	80.00	4	50.00	4	66.67	8	66.67	5	71.43	7	63.64
Participant describes no impact on relationships	2	11.11	0	0.00	2	25.00	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes a positive impact on relationships	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	1	14.29	1	9.09

Impact on relationships	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 a negative impact on relationships	12	66.67	3	37.50	15	57.69	3	30.00	10	62.50	2	100.00	2	66.67	10	66.67
Participant describes no impact on relationships	2	11.11	3	37.50	5	19.23	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes a positive impact on relationships	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.10: Impact on relationships (Subgroup variations)

Impact on relationships	More frequent	Less frequent
Participant describes relationships suffering due to their reduced capacity for socialising	Good to very good physical function	Moderate to very poor physical function Mid to low socioeconomic status

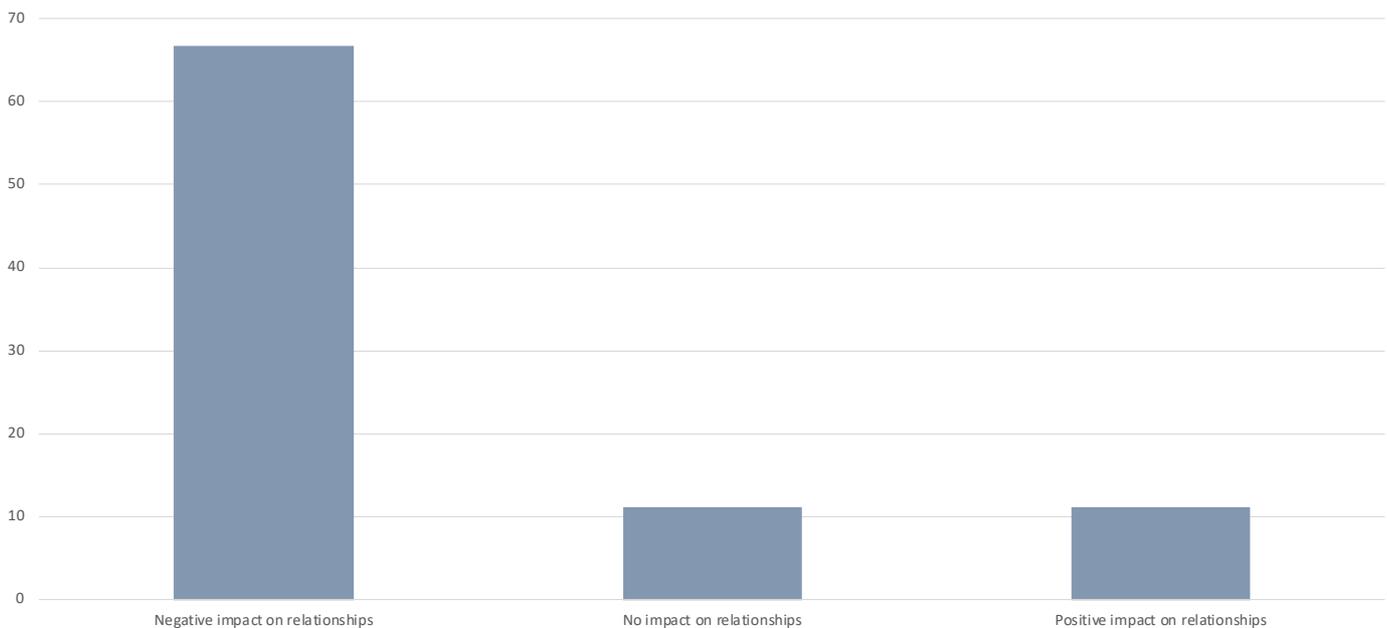


Figure 8.5: Impact on relationships

Impact on relationships: reasons

Where participants described relationships being suffering, this was primarily in relation to their reduced capacity for socialising (n=6, 33.33%).

In relation to subgroup variations, participants in the subgroup *Mid to low socioeconomic status* (16.67%) described relationships suffering due to their reduced capacity for socialising less frequently than the general NMOSD population (33.33%). No participants in the subgroup *Family and carers* (0.00%) described this.

Participant describes relationships suffering due to their reduced capacity for socialising

Yes. I just think my family don't really understand my condition and neither did my friends. My friends don't understand that I can't do everything that I used to be able to do and don't understand the fatigue and stuff because I guess they'd never experienced it before. I don't go out and do a lot of social events just because I know that I'll pay for it the next day or the next few days. Participant NMO_003

My family, yes, a little bit, I used to spend a lot of time with my nephews and nieces looking after them, and now I just don't have the energy to do that. I think my family understands that I don't have the energy, that I'm not just avoiding them or whatever. Participant NMO_010

Yes, but that's my fault. If that makes sense. I just don't jump in the car and travel and do stuff like I used to. Participant NMO_014

Participant describes no impact on relationships (general)

No. Participant NMO_002

No. Participant NMO_015

Participant describes relationships with family being strengthened

No. I think it's made it stronger. I think it's made me a stronger person, and I think it's made our relationships stronger, and I think you have a different outlook about life, and about any worries that were insignificant. I just let it go now, because it's not worth it. Participant NMO_017

I think more good than bad. Everybody has been very supportive including at his work. Participant NMOCA_003

I made a decision in the beginning that if people didn't make an effort then-- it made me choose my friends and my relationships more because life's too short to fight for something. If they're not willing to fight and want to put into it, then I won't, because I only have so much energy. There's only so many people I'll spend it on. Participant NMO_006

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

I think so. Some friends, they just don't want to hear. If you just need to get something off your chest, or whatever, that's something about you, what you're feeling, some people just go, "All right. Here she goes again." It's that brush off. Now, I pretty much don't say too much at all. Unless it's the real, real close friends, or my husband. Participant NMO_012

It has with family. I'm talking about my husband here. All of our family is back in LOCATION OVERSEAS so there's nobody here. Some friends I think have distanced themselves. [chuckles]. Participant NMOCA_006

100%, yes. 100%. Like I say, people used to go bushwalking or invite us all and have a party. They thought, "We didn't invite you because we thought NAME PERSON CARED FOR might not be up to it." [chuckles] Well, let her say, "No," that we don't want to come or whatever, but still invite us. Participant NMOCA_005

Table 8.11: Impact on relationships: reasons

Impact on relationships	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 a negative impact on relationships	12	66.67	6	66.67	6	66.67	5	62.50	7	70.00	6	66.67	6	66.67
Participant describes no impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	0	0.00	2	22.22
Participant describes a positive impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11

Impact on relationships	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 a negative impact on relationships	12	66.67	8	80.00	4	50.00	4	66.67	8	66.67	5	71.43	7	63.64
Participant describes no impact on relationships	2	11.11	0	0.00	2	25.00	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes a positive impact on relationships	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	1	14.29	1	9.09

Impact on relationships	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 a negative impact on relationships	12	66.67	3	37.50	15	57.69	3	30.00	10	62.50	2	100.00	2	66.67	10	66.67
Participant describes no impact on relationships	2	11.11	3	37.50	5	19.23	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes a positive impact on relationships	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.12: Impact on relationships: reasons (Subgroup variations)

Impact on relationships	More frequent	Less frequent
Participant describes a negative impact on relationships	Trade or high school	University

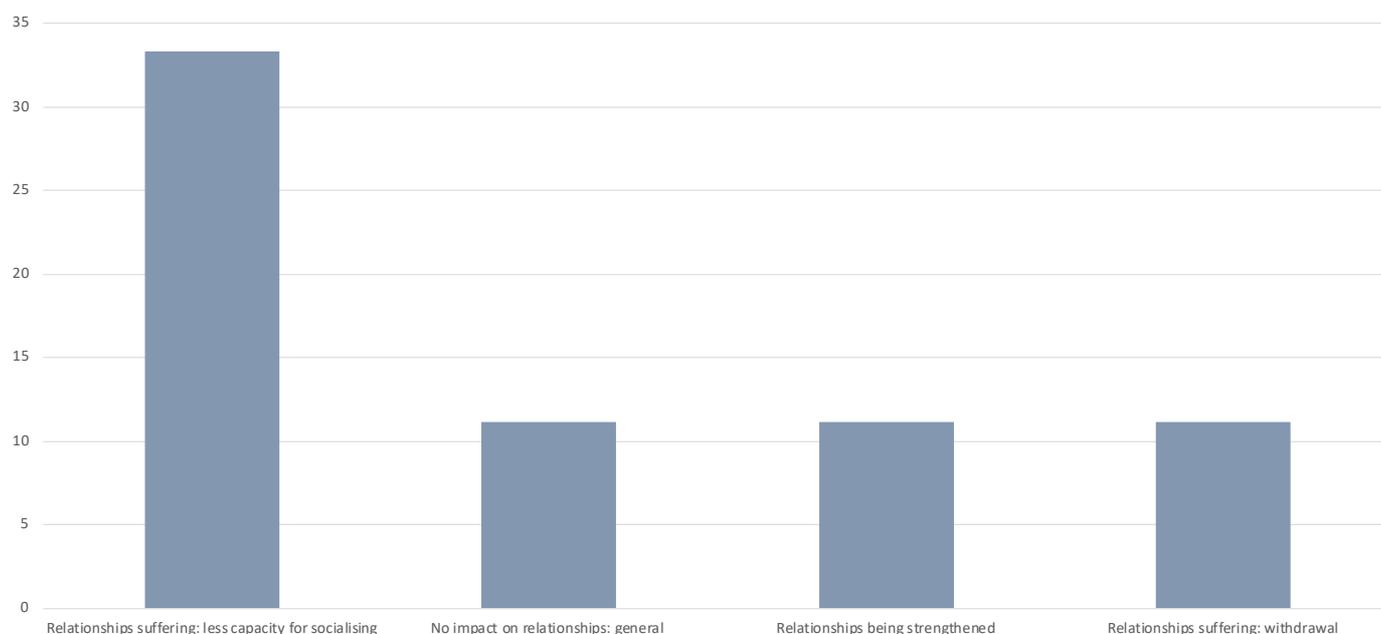


Figure 8.6: Impact on relationships: reasons

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 10 participants (55.56%) that felt there was an additional burden. Where participants felt there was an additional burden, this was primarily in relation to extra household duties and responsibilities that their family must take on (n=5, 27.78%), and needing extra assistance to get to appointments (n=5, 27.78%).

Participant gives a description suggesting that overall, there was a burden on their family

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Participant NMO_005

I think at the time of the attacks, it was a burden for them. Now that my condition has stabilised, that's not so much for me, but I definitely know for other people it is a huge burden. They have to be, yes. Family members and carers, definitely. I know, with my own children that are now adults, they had to cook the meals for me or they might have had to do more housework or they stepped up when I couldn't, and they were also studying. Participant NMO_004

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Also, one of my side effects was I've got kind of like severe warts under my feet, and nothing seemed to help them, so I've had to have chemotherapy injections under my feet. I can't walk-- Everybody helped me, my parents, my brother, and his fiancé, without them, I don't know what I would do.. Participant NMO_005

Participant gives a description suggesting that overall, there was not a burden on their family

No, it's just fine. Participant NMO_002

That's an interesting question. It's a different direction for our family, there's no doubt about that. As far as a burden, it's the cards we've been dealt, so we make the best of that. No one is annoyed at providing any assistance with that.. Participant NMOCA_004

No. I don't see it as a burden. Participant NMOCA_006

Participant describes extra household duties and responsibilities that their family must take on

They have to be, yes. Family members and carers, definitely. I know, with my own children that are now adults, they had to cook the meals for me or they might have had to do more housework or they stepped up when I couldn't, and they were also studying. Participant NMO_004

Yes. Yes [chuckles] yes, my husband has to do most things. He's doing things in the garden now and I can't go in the garden. If it's warm and sunny, I can't go out then, because the heat affects me, so I can't go outside. Participant NMO_006

With my husband, he's doing a lot more for me and my son. Obviously, the impact on him as well because he doesn't like seeing mum tired and not well. Participant NMO_008

Participant describes extra assistance needed getting to appointments

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Participant NMO_005

It is. Yes. It's probably a burden on my husband, because when I have different treatments, obviously you can't drive after treatments or different things. He has to-- because he still works. Participant NMO_013

I didn't need help showering and stuff, or anything like that, but just going to appointments, getting to my treatments. I relied on my family a lot for that. Participant NMO_017

Table 8.13: Burden on family

Burden on family	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 extra household duties and responsibilities that their family must take on	5	27.78	2	22.22	3	33.33	3	37.50	2	20.00	2	22.22	3	33.33
Participant describes extra assistance needed getting to appointments	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	1	11.11	4	44.44
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	0	0.00	2	22.22
Participant describes their condition being a burden in general (No specific examples)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	2	22.22	0	0.00
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	3	33.33	7	77.78	3	37.50	7	70.00	7	77.78	3	33.33
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	0	0.00	2	22.22

Burden on family	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 extra household duties and responsibilities that their family must take on	5	27.78	2	20.00	3	37.50	0	0.00	5	41.67	2	28.57	3	27.27
Participant describes extra assistance needed getting to appointments	5	27.78	2	20.00	3	37.50	2	33.33	3	25.00	1	14.29	4	36.36
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes their condition being a burden in general (No specific examples)	2	11.11	2	20.00	0	0.00	2	33.33	0	0.00	1	14.29	1	9.09
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	8	80.00	2	25.00	4	66.67	6	50.00	3	42.86	7	63.64
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09

Burden on family	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 extra household duties and responsibilities that their family must take on	5	27.78	0	0.00	5	19.23	1	10.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes extra assistance needed getting to appointments	5	27.78	0	0.00	5	19.23	0	0.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	2	25.00	4	15.38	4	40.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes their condition being a burden in general (No specific examples)	2	11.11	2	25.00	4	15.38	3	30.00	1	6.25	1	50.00	1	33.33	1	6.67
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	6	75.00	16	61.54	3	30.00	8	50.00	2	100.00	3	100.00	7	46.67
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	2	25.00	4	15.38	5	50.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.14: Burden on family (Subgroup variations)

Burden on family	More frequent	Less frequent
Participant describes extra household duties and responsibilities that their family must take on	Higher socioeconomic status	Mid to low socioeconomic status
Participant describes extra assistance needed getting to appointments	Good to very good physical function	Moderate to very poor physical function Aged 18 to 44
Participant gives a description suggesting that overall, there was a burden on their family	More relapses High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Fewer relapses Low to moderate fear Good to very good physical function University Aged 18 to 44

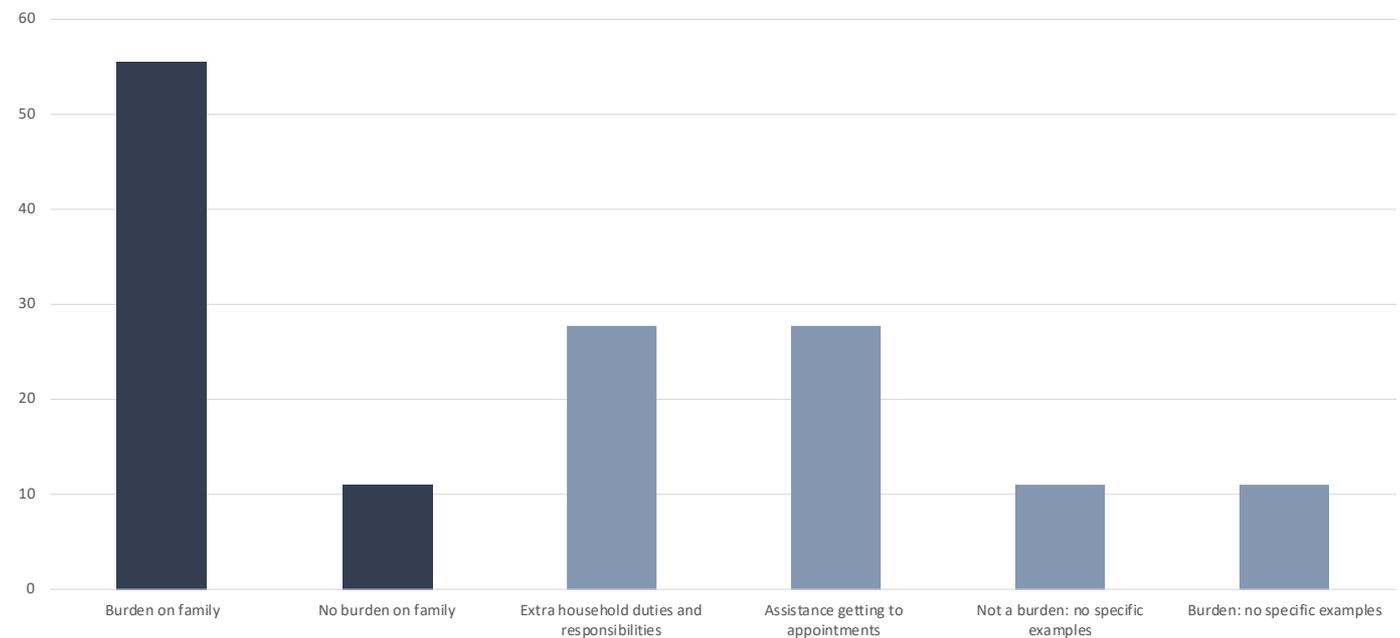


Figure 8.7: Burden on family

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 14 participants (77.78%) that gave a description suggesting that overall there was at least some cost burden. There were 10 participants (55.56%) that spoke about cost burden in relation to needing to take time off work and nine participants (50.00%) that reported cost burden in relation to the cost of treatments (including repeat scripts).

Participant gives a description suggesting that overall, there was at least some cost burden

Obviously, I lost my job, my career, so that was pretty big financial burden. Participant NMO_003

Oh, I've lost my job. I don't work now. That's had a huge impact on our lives. My husband is working two jobs to keep the house, the mortgage and all those kinds of things. Participant NMO_006

Yes, it was huge. When I was first referred for MRI, they cost about \$1,400 and because I hadn't been

referred by a neurologist yet, I had to pay those upfront. Participant NMO_010

Participant gives a description suggesting that overall, there was no cost burden

Everything I've gone through the public system, I have got private cover, so I do sign for them to claim on my medical funds. All the MRIs, everything, its all been for free. Participant NMO_007

I've really had no cost associated with it because I've gone public the whole time. Even my MRIs are all done at a hospital, I don't pay for them. Participant NMO_017

I think we have been fairly lucky in a sense, apart from the first assessment before he was diagnosed and everything has been pretty much paid for. The treatment is free, blood test only because there's this CD19 component. You'd have to go from LOCATION METROPOLITAN to LOCATION METROPOLITAN so that there wasn't extra cost for them. Participant NMOCA_003

Participant describes a cost burden in relation to needing to take time off work

The cost of my husband having a lot of time off work for me to go to my hospital appointment. Participant NMO_012

I actually had to give up work and I tried to work part-time but I couldn't. She needed me a lot more and I couldn't cope with working as well as looking after NAME PERSON CARED FOR. Participant NMO_016

Oh. I've lost my job. I don't work now. That's had a huge impact on our lives. My husband is working two jobs to keep the house, the mortgage and all those kinds of things. Participant NMO_006

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

I was just sent to the neuro physio and I didn't have to pay for that, but all the medications and everything I had to pay for. Participant NMO_010

As well as my financial situation changed because I was no longer able to work. Then you've got the cost of your immunosuppression every month. It's not a huge cost, but over several years, it adds up. Luckily, all my yearly MRIs and tests are all put through the public health system. When I've been to hospital, it's all been covered. That part of it isn't there, but it's the extra huge cost to my superannuation and my working life and cost of pharmaceutical stuff, having to constantly be on drugs, that it is the expense. Participant NMO_004

Participant describes a cost burden in relation to a family member needing to take time off work

The cost of my husband having a lot of time off work for me to go to my hospital appointment. Participant NMO_012

Well my husband will have to take some time off work when I got sick. I don't work so that helped, it didn't make a difference with me but obviously, my husband will have to take on much, well because we've got a child as well. He will have to do school duties and stuff like that. Just the time because scan to scan, you just have to take time out. Participant NMO_001

Well, the human cost is huge, because I remember my son, every time I had an attack at school, and I'd be in the corridor not being able to walk down the car and they'd call an ambulance. Because my son was working locally, he was the one that dropped his tools, I missed out on work, he missed out on work. Participant NMO_004

Participant describes no cost burden and that nearly everything was paid for through the health system

Everything I've gone through the public system, I have got private cover, so I do sign for them to claim on my medical funds. All the MRIs, everything, its all been for free. Participant NMO_007

I've really had no cost associated with it because I've gone public the whole time. Even my MRIs are all done at a hospital, I don't pay for them. Participant NMO_017

Table 8.15: Cost considerations

Cost considerations	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 a cost burden in relation to needing to take time off work	10	55.56	4	44.44	6	66.67	4	50.00	6	60.00	3	33.33	7	77.78
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	4	44.44	5	55.56	5	62.50	4	40.00	4	44.44	5	55.56
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	7	77.78	7	77.78	6	75.00	8	80.00	6	66.67	8	88.89
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	1	11.11	2	22.22	2	25.00	1	10.00	2	22.22	1	11.11

Cost considerations	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 a cost burden in relation to needing to take time off work	10	55.56	6	60.00	4	50.00	4	66.67	6	50.00	5	71.43	5	45.45
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	5	50.00	4	50.00	3	50.00	6	50.00	6	85.71	3	27.27
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	14.29	2	18.18
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	0	0.00	2	18.18
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	8	80.00	6	75.00	5	83.33	9	75.00	7	100.00	7	63.64
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27

Cost considerations	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 a cost burden in relation to needing to take time off work	10	55.56	6	75.00	16	61.54	2	20.00	10	62.50	0	0.00	1	33.33	9	60.00
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	2	25.00	11	42.31	1	10.00	8	50.00	1	50.00	1	33.33	8	53.33
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	0	0.00	3	11.54	4	40.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	12.50	3	11.54	2	20.00	1	6.25	1	50.00	0	0.00	2	13.33
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	7	87.50	21	80.77	7	70.00	13	81.25	1	50.00	2	66.67	12	80.00
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	1	33.33	2	13.33

Table 8.16: Cost considerations (Subgroup variations)

Cost considerations	More frequent	Less frequent
Participant describes a cost burden in relation to needing to take time off work	More relapses Moderate to very poor physical function Mid to low socioeconomic status Aged 18 to 44	Fewer relapses Moderate to very poor physical function Aged 45 or older
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Low to moderate fear Aged 18 to 44	High to very high fear Aged 45 or older
Participant gives a description suggesting that overall, there was at least some cost burden	Good to very good physical function Aged 18 to 44	Moderate to very poor physical function Aged 45 or older

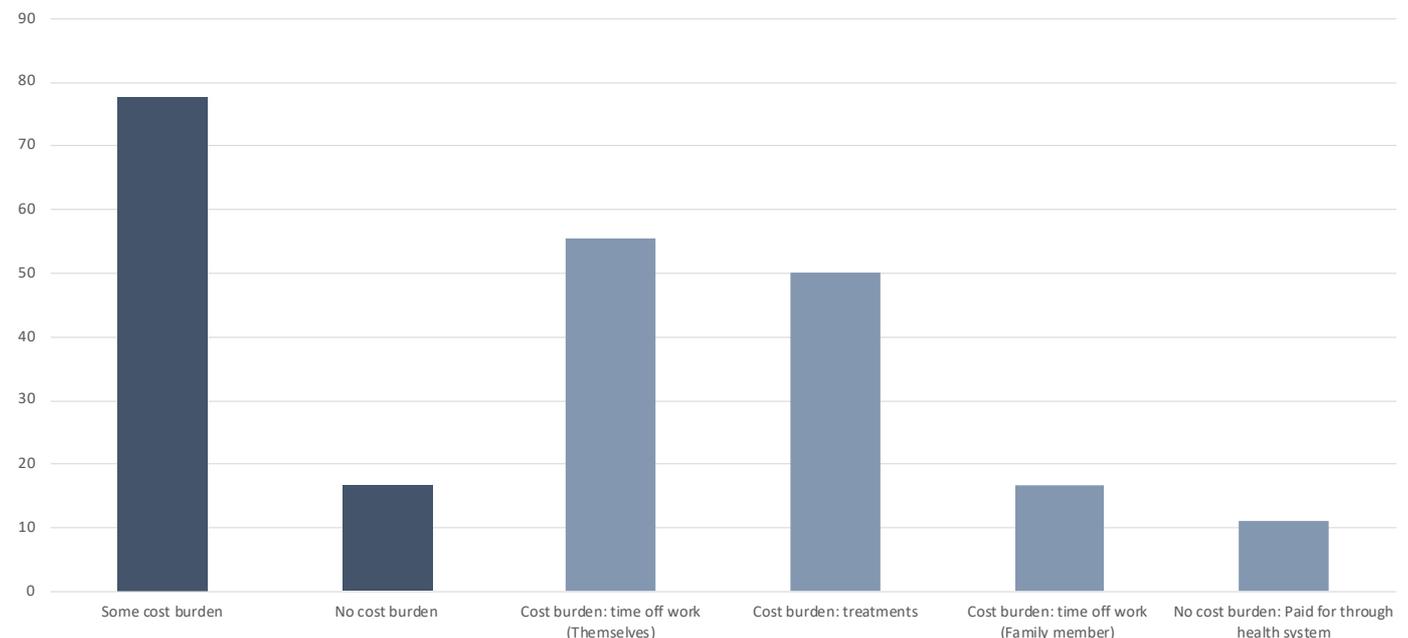


Figure 8.8: Cost considerations

Overall impact of NMOSD on quality of life

In the online questionnaire, participants were asked to rate the overall impact of having a NMOSD or MOG on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is Life was great (Table 8.17, Figure 8.9).

NMOSD

The median impact of quality of life from NMOSD was 2.00 (IQR= 1.28), in the “life was distressing” range.

MOG

The median impact of quality of life from MOG was 3.00 (IQR= 0.25), in the “life was a little distressing” range

NMOSD or MOG

The median impact of quality of life from NMOSD or MOG was 2.50 (IQR= 0.27), in the “life was distressing” to “life was a little distressing” range

Table 8.17: Overall impact of NMOSD on quality of life

Impact of condition on quality of life	Participants with NMOSD		Participants with MOG		Participants with NMO or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
1 Life is/was very distressing	4	22.22	0	0.00	4	15.38
2 Life is/was distressing	7	38.89	2	25.00	9	34.62
3 Life is/was a little distressing	1	5.56	6	75.00	7	26.92
4 Life is/was average	4	22.22	0	0.00	4	15.38
5 Life is/was good	1	5.56	0	0.00	1	3.85
6 Life is/was very good	0	0.00	0	0.00	0	0.00
7 Life is/was great	10	55.56	0	0.00	1	3.85

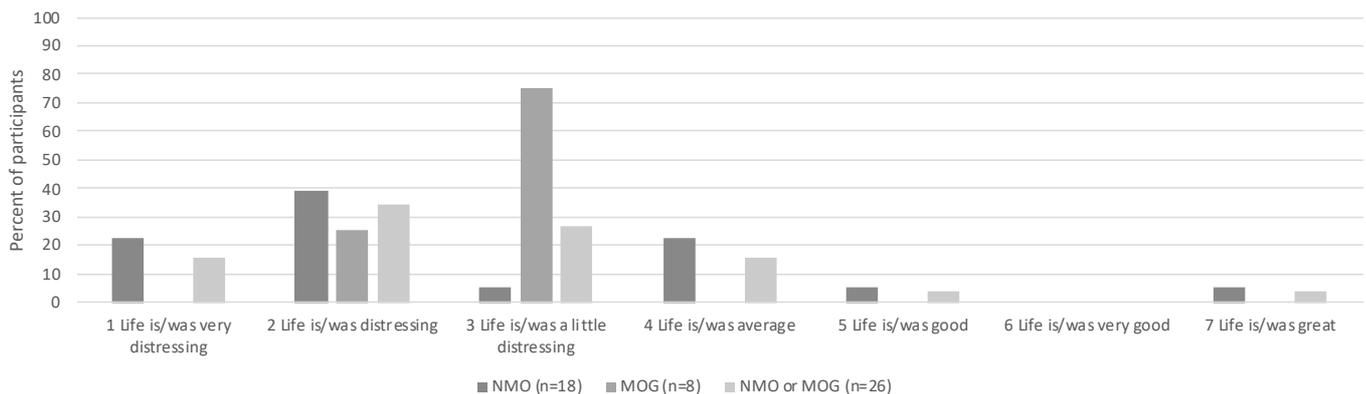


Figure 8.9: Overall impact of NMOSD on quality of life

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.8. Overall the NMOSD cohort had a mean total score of 41.33 (SD = 8.90), which corresponds to high levels of anxiety (Table 8.18)

Comparisons of Fear of progression have been made based on **participant type** (Tables 8.19 to 8.20,

Figure 8.10), **relapse** (Table 8.21, Figure 8.11), **physical function** (Table 8.22, Figure 8.12), **education**, (Table 8.23, Figure 8.13), **socioeconomic advantage** (Tables 8.24, Figure 8.15), **age** (Table 8.25, Figure 8.15), **gender** (Table 8.26), and **location** (Table 8.27). No analysis by the **fear of progression** subgroups have been conducted to avoid bias.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their condition. Overall, the average fear of progression score for NMOSD participants in this study indicated high levels of anxiety.

Table 8.18: Fear of progression summary statistics

Fear of progression	Mean	SD	Median	IQR	Possible range	Quintile
NMOSD* (n=18)	41.33	8.90	41.5	12.5	12 to 60	4

*Normal distribution use mean and SD as measure of central tendency

Comparisons of Fear of progression total score scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or MOG* groups were included in the *NMOSD and MOG* subgroup (n=26, 72.22%), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Boxplots of each Fear of progression total score scale by **participant type** are displayed in Figure 8.10, summary statistics are displayed in Tables 8.19 and 8.20.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 8.19). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 8.20).

A one way ANOVA test indicated a statistically significant difference in the **Fear of progression total score** scale between groups, $F(3, 58) = 4.83, p = 0.0045$ (Table 8.10).

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Family and carer* subgroup (Mean = 28.90, SD = 11.66) was significantly lower (less anxiety) compared to participants in the *NMOSD* (Mean = 41.33, SD = 8.90, $p = 0.0083$), *MOG* (Mean = 41.50, SD = 9.68, $p = 0.0343$), and *NMOSD or MOG* (Mean = 41.38, SD = 8.95, $p = 0.0044$) subgroups.

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition, with a higher score denoting increased anxiety. On average, participants in the *Family and carer* subgroup scored lower than participants in the *NMOSD*, *MOG*, and *NMOSD or MOG* subgroups. This indicates that participants in the *Family and carer* subgroup were a little anxious, and those in the *NMOSD*, *MOG*, and *NMOSD or MOG* subgroups, were very anxious about their condition.

Table 8.19: Fear of progression total score by participant type ANOVA test

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	NMOSD	18	50.00	41.33	8.90	Between groups	1307.00	3	435.80	4.83	0.0045*
	MOG	8	22.22	41.50	9.68	Within groups	5231.00	58	90.20		
	NMOSD and MOG	26	72.22	41.38	8.95	Total	6538.00	61			
	Family and carers	10	27.78	28.90	11.66						

*significant at $p < 0.05$

Table 8.20: Fear of progression total score by participant type post hoc Tukey HSD test

Fear of progression	Group	Difference	Lower	Upper	P adjusted
Total score	MOG - NMOSD	0.17	-10.51	10.84	1.0000
	NMOSD and MOG - NMOSD	0.05	-7.65	7.75	1.0000
	Family and carers - NMOSD	-12.43	-22.34	-2.53	0.0083*
	NMOSD - MOG	-0.12	-10.27	10.04	1.0000
	Family and carers - MOG	-12.60	-24.52	-0.68	0.0343*
	Family and carers - NMOSD and MOG	-12.48	-21.83	-3.14	0.0044*

*significant at $p < 0.05$

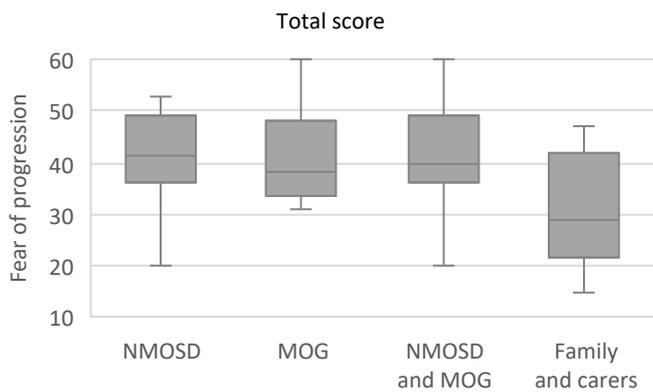


Figure 8.10: Boxplot of Fear of progression total score by participant type

Comparisons of Fear of progression total score scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **relapse** are displayed in Figure 8.11, summary statistics are displayed in Table 8.21. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.21).

No significant differences were observed between participants in the subgroup *Fewer relapses* compared to those in the *More relapses* subgroup for the Fear of progression total score.

Table 8.21: Fear of progression total score by relapse summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	<i>Fewer relapses</i>	9	50.00	40.00	7.47	-0.62	16	0.5416
	<i>More relapses</i>	9	50.00	42.67	10.43			

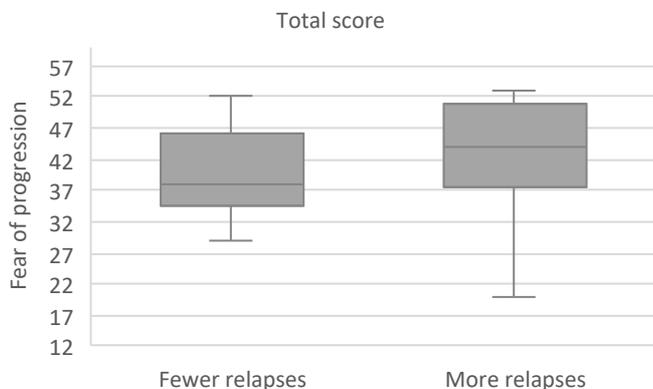


Figure 8.11: Boxplot of Fear of progression total score by relapse

Comparisons of Fear of progression total score scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup

(n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **physical function** are displayed in Figure 8.12, summary statistics are displayed in Table 8.22. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.22).

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for the Fear of progression total score.

Table 8.22: Fear of progression total score by physical function summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	<i>Moderate to very poor physical function</i>	9	50.00	43.67	7.94	1.12	16	0.2792
	<i>Good to very good physical function</i>	9	50.00	39.00	9.66			

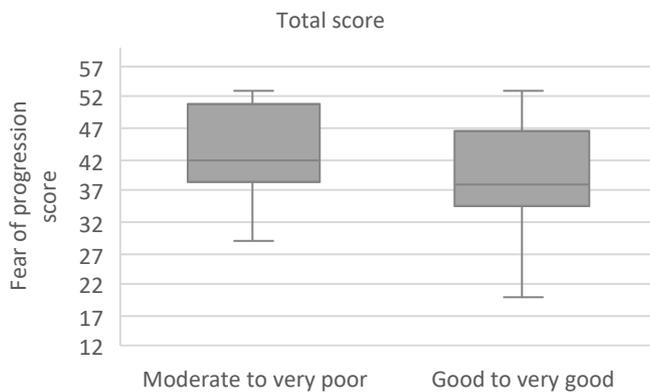


Figure 8.12: Boxplot of Fear of progression total score by physical function

Comparisons of Fear of progression total score scales by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **education** are displayed in Figure 8.13, summary statistics are displayed in Table 8.23. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.23).

A two sample t-test indicated that the mean score for the **Fear of progression total score** [t(16) =

0.0122 p=0.0122] was significantly higher (less anxiety) for participants in the *Trade or high school* subgroup (Mean = 45.80, SD = 5.67) compared to participants in the *University* subgroup (Mean = 35.75, SD = 9.33).

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition, with a higher score denoting increased anxiety. On average, participants in the *University* subgroup scored lower than participants in the *Trade or high school* subgroups. This indicates that participants in the *University* subgroup were a little anxious, and those in the *Trade or high school* subgroup, were moderately anxious about their condition.

Table 8.23: Fear of progression total score by education summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	Trade or high school	10	55.56	45.80	5.67	2.83	16	0.0122*
	University	8	44.44	35.75	9.33			

*significant at p<0.05

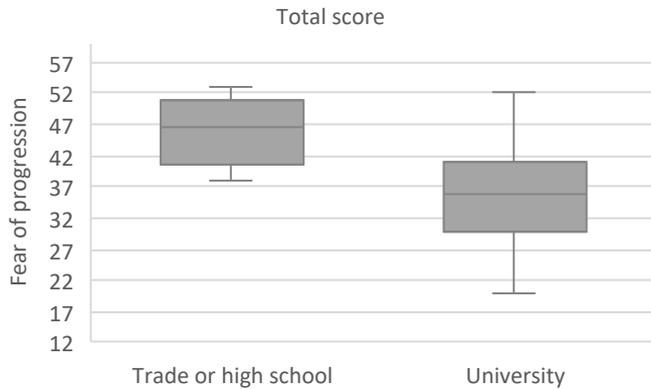


Figure 8.13: Boxplot of Fear of progression total score by education

Comparisons of Fear of progression total score scales by socioeconomic status

Comparisons were made by socioeconomic advantage, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=12, 66.67%). Only participants with NMOSD were included in this comparison.

Boxplot of the Fear of progression total score scale by **socioeconomic advantage** are displayed in Figure 8.14, summary statistics are displayed in Table 8.24. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.24).

No significant differences were observed between participants in the *Mid to low status* subgroup compared to those in the *Higher status* subgroup for the **Fear of progression total score**.

Table 8.24: Fear of progression total score by socioeconomic status summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	Mid to low status	6	33.33	44.50	5.47	1.07	16	0.2998
	Higher status	12	66.67	39.75	10.04			

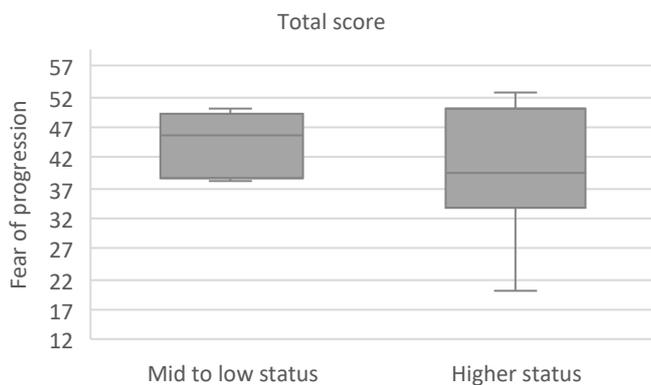


Figure 8.14: Boxplot of Fear of progression total score by socioeconomic status

Comparisons of Fear of progression total score scales by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **age** are displayed in Figure 8.15, summary statistics are displayed in Table 8.25. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.25).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* for the fear of progression total score.

Table 8.25: Fear of progression total score by age summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	<i>Aged 18 to 44</i>	7	38.89	40.57	11.75	-0.28	16	0.7818
	<i>Aged 45 or older</i>	11	61.11	41.82	7.17			

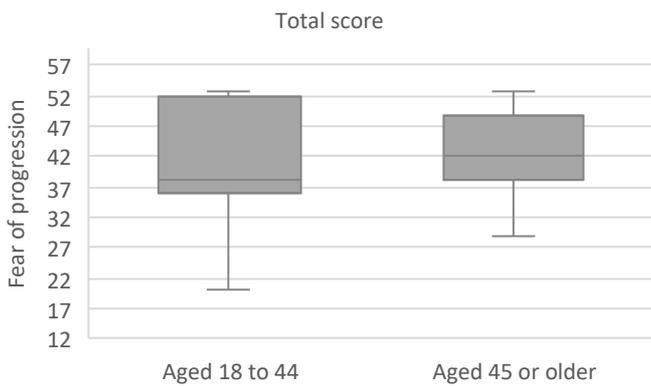


Figure 8.15: Boxplot of Fear of progression total score by age

Comparisons of Fear of progression total score scales by gender

There were 16 *Females* (n=16, 88.89%) with NMOSD, however, there were too few *Males* (n=2,

11.11%) for comparisons to be made. Data by gender is displayed for NMOSD participants in Table 8.26, but no analysis conducted.

Table 8.26: Fear of progression total score by gender summary statistics

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Total score	<i>Female</i>	16	88.89	40.06	8.61	40.00	9.25
	<i>Male</i>	2	11.11	51.50	2.12	51.50	1.50

Comparisons of Fear of progression total score scales by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15

participants with NMOSD (83.33%) that lived in *Metropolitan* areas, however, too few participants with NMOSD lived in *Regional or remote* areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants is displayed in Table 8.27, but no analysis conducted.

Table 8.27: Fear of progression total score by location summary statistics

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Total score	<i>Female</i>	16	88.89	40.06	8.61	40.00	9.25
	<i>Male</i>	2	11.11	51.50	2.12	51.50	1.50

Fear of progression: individual questions by NMOSD

The responses to individual questions of the Fear of Progression questionnaire for participants with NMOSD are displayed in Table 8.19, and Figure 8.15.

There were 50% or more participants that were often or very often worried about; disease progression (n=11, 61.11%), reaching professional or personal goals (n=12, 66.67%), relatives being diagnosed with disease (n=9, 50.00%), being able to pursue hobbies (n=15, 83.33%), treatment will damage body (n=11, 61.11%), worried about family if anything happens to them (n=11, 61.11%), and not being able to work (n=9, 50.00%).

Table 8.28: Fear of progression questionnaire: individual questions by NMOSD

Fear of progression	Never to sometimes		Often and Very often	
	n=18	%	n=18	%
I become anxious if I think my disease may progress	7	38.89	11	61.11
I am nervous prior to doctors appointments or periodic examinations	10	55.56	8	44.44
I am afraid of pain	12	66.67	6	33.33
I have concerns about reaching my professional and/or personal goals because of my illness	6	33.33	12	66.67
When I am anxious, I have physical symptoms such as a rapid heartbeat, stomach ache or agitation	15	83.33	3	16.67
The possibility of my relatives being diagnosed with this disease disturbs me	9	50.00	9	50.00
It disturbs me that I may have to rely on strangers for activities of daily living	10	55.56	8	44.44
I am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	3	16.67	15	83.33
I am afraid of severe medical treatments during the course of my illness	11	61.11	7	38.89
I worry that my treatment could damage my body	7	38.89	11	61.11
I worry about what will become of my family if something should happen to me	7	38.89	11	61.11
The thought that I might not be able to work due to my illness disturbs me	9	50.00	9	50.00
If I am on a treatment and it is working well for me (limited side effects, no progression of disease), I worry what will happen if I stop treatment	10	55.56	8	44.44
I become anxious if I am not experiencing any side effects of treatment as it makes me think that the treatment isn't working	18	100.00	0	0.00

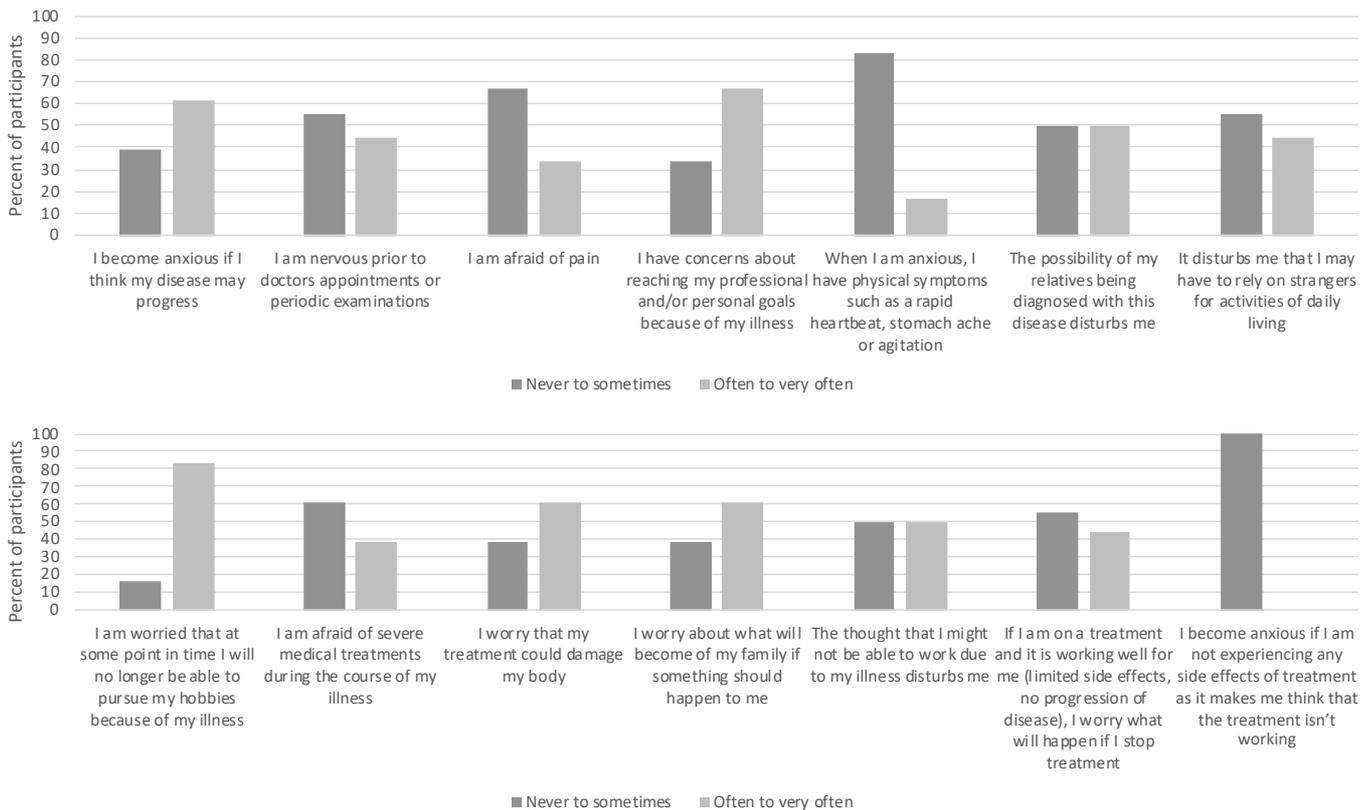


Figure 8.16: Fear of progression questionnaire: individual questions by NMOSD

Fear of progression question by question

The average score for each of the 12 fear of progression questions are presented in Table 8.29 and Figure 8.17. For each question, participants respond to each question using the following scale:

- Never
- Seldom
- Sometimes
- Often
- Very often

A numerical score is given for each response, where “Never” is equal to 1, and “Very often” is equal to 5. A higher score denotes more anxiety.

Participants in this study were most anxious about:

- Being unable to pursue hobbies
- Their family if something happens to them
- Reaching professional and personal goals
- Disease progression

Table 8.29: Fear of progression question by question overview

Question	Average score
become anxious if I think my disease may progress	3.78
I am nervous prior to doctors appointments or periodic examinations	3.56
I am afraid of pain	3.11
I have concerns about reaching my professional and/or personal goals because of my illness:	3.83
When I am anxious, I have physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.67
The possibility of my relatives being diagnosed with this disease disturbs me	3.22
It disturbs me that I may have to rely on strangers for activities of daily living	3.33
I am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	4.17
I am afraid of severe medical treatments during the course of my illness	3.06
I worry that my treatment could damage my body	3.39
I worry about what will become of my family if something should happen to me	4.00
The thought that I might not be able to work due to my illness disturbs me	3.22

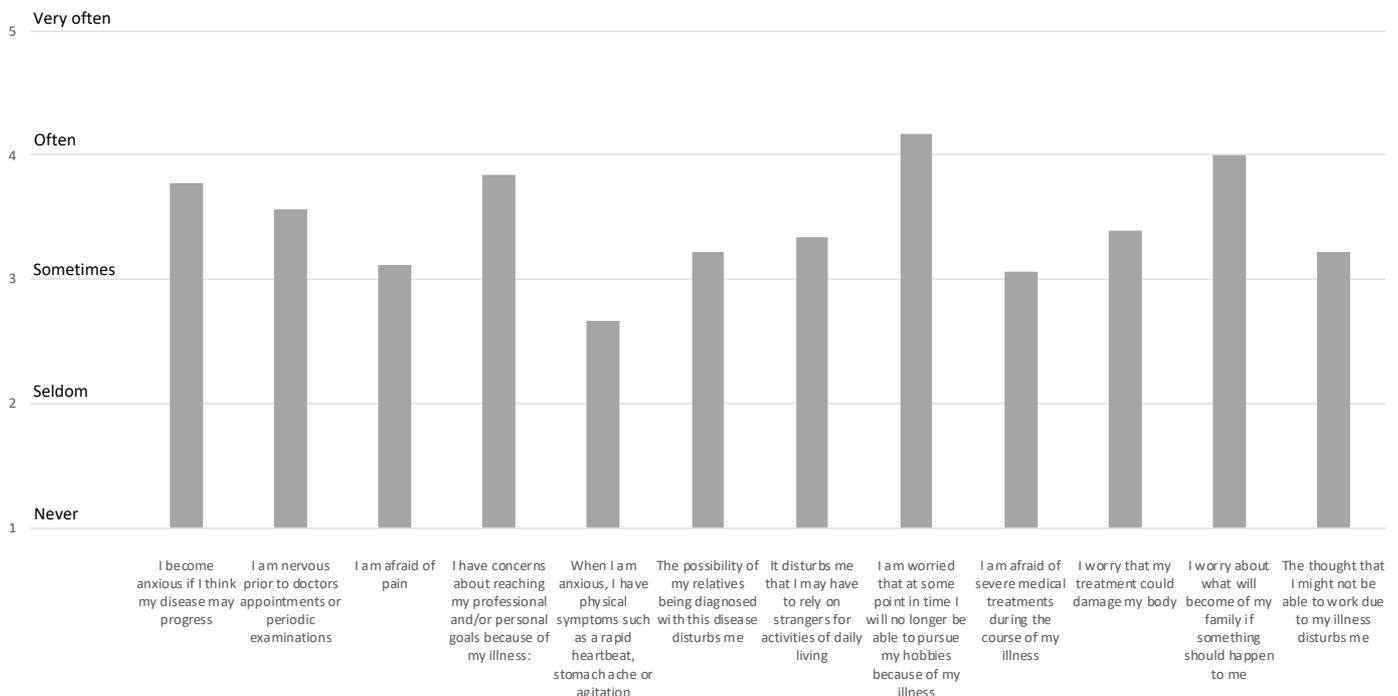


Figure 8.17: Fear of progression question by question overview