

# Community Roundtable

You can watch the video of this event at: [youtu.be/m5hzT2EkVQk](https://youtu.be/m5hzT2EkVQk)

[00:00:05] **Skye Corken:** Welcome everybody to ADEM Together and welcome specifically to our Community Roundtable. My name is Skye Corken and I'm the communication and engagement coordinator with SRNA and I have with me today three very special guests, Nancy, Graeme, and Adam, who I'm going to let introduce themselves in just a moment. But really quickly, before we get started, if you have any questions for our guest speakers today, there is a Q&A section that you can put your questions there in and we will do our best to address those throughout the conversation. So, we will have some time for some Q&A today.

[00:00:47] And then, if you have any concerns, we also have the lovely Krissy who is in the chat as well, so she can help direct you if you're having any issues. So, let's go ahead and get started. I'm going to be really respectful of our time today. I just wanted you guys to go ahead and introduce yourselves to each other and to the audience. So, Nancy, Graeme, Adam, do one of you want to go ahead and go first?

[00:01:13] **Adam O'Connor:** Ladies first.

[00:01:15] **Sutxwaan / Nancy J. Furlow:** My Tlingit name is Sutxwaan, and my name is Nancy Furlow. I live in a small island community in Southeast Alaska. I received my health care at Indian healthcare facilities. And so, Sitka where I live has a hospital for all of Southeast Alaska, IHS Hospital. But Anchorage where I am right now has a larger hospital and this is where all our specialists are. So, they sometimes fly down to our community and it's a two-and-a-half-hour flight between Sitka here and Anchorage. So, I actually have MOG with ADEM and optic neuritis. I'm 68 years old. So, I'm at the older end of the spectrum. So, I'm a little bit unique. I'm the oldest one here today. And so, thank you very much, Skye, for inviting us and SRNA for offering these podcasts, so that people can know about those of us with these rare neuroimmune diseases.

[00:02:32] **Skye Corken:** Thank you, Nancy. Thank you so much for being here. Graeme, Adam, do you want to go ahead and go next?

[00:02:39] **Graeme Mackenzie:** Sure. My name is Graeme Mackenzie. I'm 53. Two years ago, right this week, I got the AstraZeneca vaccine and that was my trigger that started this MOGAD journey. I started with just fainting at like place of employment and spent about five days in and out of the emergency room and then was ambulated to Foothills Hospital in Calgary. I was living in Banff, Alberta at the time, sent to the Foothills Hospital in Calgary. And about the next 10 days, I don't really remember. At one point there, they offered me either IVIG or steroids as the treatment and we didn't know anything about any of this and we'd guessed at IVIG, and it worked. And about day three of the treatment, I started to progress.

[00:03:45] I presented with ADEM, full body shutdown, just couldn't really get out of bed move, walk, pee, talk. I could talk and that was about it. And then just over the last two years have been working hard to try

and get back to being mobile and it took till the following February for me to get the MOG diagnosis. They just thought it was ADEM for a while and then finally figured out that I have MOGAD. That's probably enough of an introduction, I guess.

[00:04:20] **Skye Corken:** No, that's great. Thank you. It's great to have people who are on different levels in terms of their journey with their diagnosis. I think it brings all kinds of different perspectives into the conversation. So, thank you Graeme for being here with us today. Adam, do you want to go ahead and say hi?

[00:04:42] **Adam O'Connor:** My name is **Adam O'Connor**. I had my ADEM onset 10 years ago. It was a virus of some sort that just wiped me out. My then wife took me to the hospital, they admitted me, I was declining pretty rapidly, just generally, whole body shut down, just like you said Graeme and everything that comes with that. So, they put me in a medically induced coma, and I was actually in the hospital for three months. But towards the end of that, they had done the IVIG and that's what started this miraculous turnaround. But when they did bring me out of the medically induced coma, I recall the first thing the doctor said was, "this is what's going on, and we believe that you should be able to walk again," which is a pretty jarring thing to hear when you don't even know what you had just been through.

[00:05:30] But that was the motivation I needed to hear because I'm not going to have somebody tell me to think I'm going to be able to walk again. So, I've put in the work, and I had a great medical team and over the course of the next several months, everything really rapidly improved. It's been remarkable, like I said, it was 10 years ago and I'm very fortunate to be in a position where I lead a very whatever normal life would look like. So, I'm here to try and help talk anybody through whatever would be resource for whatever I can. And I went through some, some pretty bad stuff. At one point I told my ex-wife that my death was imminent and that they should look at getting my last rights. And so that was a pretty serious thing. And for me to be here now is remarkable and I'm thankful.

[00:06:20] **Skye Corken:** Thank you. I think I'd love to dive into that a little bit more as well. But I think I want to start off with my first question. This is—obviously, we're a few months in now to our awareness month events and this isn't our first community roundtable we've had. But one question that we've been asking all of our participants in these roundtables is have you found a new normal? And if so, how? A lot of our community members have discussed this in different ways throughout the years with a concern about adjusting to a new normal and feeling like you're grieving a little bit of your old life and really coming to terms with that. And there's been a lot of our community members that have also found a really wonderful new normal and they're really happy with the way things are going right now. So really, that's my long way of asking just like how your life has changed since your diagnosis? And have you found a "new normal"? And if so, do you mind sharing how with the audience today? Nancy, do you want to go first with that question?

[00:07:35] **Sutxwaan / Nancy J. Furlow:** Sure. Like Adam and Graeme, I was completely paralyzed in my lower body and everything that's involved with your lower body and upper body weakness. I have neurologic issues, spatial issues. My spinal cord, brainstem, brain, and optic nerves are involved. So, my own personal experience of my entire body changed. It was like being dropped in a different body and it took a while to get used to it. I still have moments where I think, "Oh my goodness, what is going on?" And I'm not stable yet, completely stable. So, I have periods that are more challenging and less challenging. Sitka is on the water, so I get to look out my kitchen window and see the little piece of the ocean every day. And some days it's calmer. Some days it's stormier.

[00:08:34] And I've learned that up and down movement is my new normal. Sometimes it's a calm movement and things that are happening to me, it's like, okay, I've experienced that before. Sometimes it's crazy rough.

Three weeks ago today, I was hospitalized briefly, and I always begin by losing my ability to walk. And so, I've had to learn to be okay with continually learning to teach my muscles what to do and then I lose all of it and sometimes I go even further back and then I get stronger and then something happens, and I move back. So, getting comfortable with that waves and accepting that I do have a very rare neuroimmune disease and that's okay. That's all right. It's not scary anymore. It was in the beginning, but it's not really scary anymore.

[00:09:49] And just - I have incredible people around me as well. And I created a MOG what I call my MOG team. So it's people, my daughter is here in Anchorage where I am right now and like Adam, I had to do a will and make her medical power of attorney, but I also have people locally in Sitka on that team who if something's happening to me, I call them and put them either on a soft alert, which means something's happening or a hard alert, which means I may need to go to the ER and they need to check on me because if I am relapsing, I lose my ability to make decisions and I learned that the hard way. So it's just like accepting who we are, paying attention to our bodies, what's going on, being comfortable admitting I can't do this or I can't do that and I need help and it doesn't mean that there's something wrong with us or that we're - like at first I felt like, what's going on with me, but now, it's just like, okay, this is the way it is and it's okay and in this new normal that I'm in, it has a variety of experiences for me.

[00:11:16] **Skye Corken:** Thank you for sharing. I'm glad you touched on your personal support and the people around you because I do want to get into that in a little bit and what that looks like for each of you. But having the right team and the right people surrounding you is everything. It's not only just of course your medical professionals and your neurologists that you're connecting with, but your family and your friends and having plans in place and Nancy, it sounds like you have that, which is great. Adam or Graeme, do you want to answer this next one for you?

[00:11:54] **Graeme Mackenzie:** Go ahead, Adam.

[00:11:56] **Adam O'Connor:** Sure. Boy a lot has changed. Physically, I've learned to really make sure that I'm more in tune with what my body is doing. I may be able to listen to it a lot more. I know that, when I feel things, that are different, that's something that I don't think that I was aware of prior to the onset of ADEM. So, I just pay a lot more attention to myself, but generally, and something that I think needs to be spoken about perhaps a little bit more, it's just the mental health aspect of all of it, especially with May being mental health month.

[00:12:33] I definitely think that, like you said, Nancy, definitely you need a team or a group of people as support and for me, it was in a near death experience. So, it changed my outlook entirely. And I'm grateful to be here. I'm grateful for the people that were there for me then or that are there for me now or that check in or when I post on social media about anything about ADEM, or rare disease month or whatnot, it's something that turns into a conversation and so really just making sure that the mental health aspect is core to what you're working on as well. And that's something that I've been fortunate in the past 10 years to be able to focus on. So that's something I know that people get lost in and that's a key component for my rebound at least.

[00:13:29] **Skye Corken:** Yeah, definitely. Thank you, Adam. Graeme?

[00:13:37] **Graeme Mackenzie:** I had a year, pretty much of - I was three. Well, just about eight weeks in hospital and then took me almost a full year exactly to be able to get back to work part time on a graduated return. And when I first started coming out after IVIG and being able to - my first little bit of physio was sit up, lay down, sit up, lay down, have a nap and it just built slowly from there. I firmly believe that part of my recovery is just being stubbornly active, pushing to the limit sometimes too far, but just always trying to be doing something. And I think that helped all the nerves re-fire.

[00:14:27] I noticed very much early on in hospital whenever I would try some kind of a new physio exercise or drill or step or something, I'd have a headache after. And it seems like that headache related to the nerves trying to re-jig themselves and realign themselves. I was on Aspirin and Tylenol for quite a while, or Ibuprofen and Tylenol for quite a while. But the headaches broke through that, and it seemed the more active I was, the bigger the headaches got. So, I just kept doing stuff and suffering through the headaches. And now, I'm like a highly functional damaged human. I can ski, I can bike, I'm back full time working, driving, doing everything.

[00:15:18] So I think the biggest change for me mentally wise is the fear of getting sick and having it retriggered. So, I'm nowhere near as social as I used to be. I'm not going to be around crowds or around a lot of people that I don't really know, even sometimes being around people you know is hard because you're not sure who they've been around. So, the cloud that hangs over of relapse - I don't think I've had a relapse yet. I've had pseudo relapses where you get tingling and strain sensations and twitching in the muscles and stuff, but that cloud hangs over you regardless of how bright your day is, it's still there. So, we're trying to just keep working through that as we go along.

[00:16:15] **Skye Corken:** Thank you, Graeme. Nancy, if you don't mind, I wanted to speak to you just a little bit because you and I actually met at a support group meeting last year and it was just a couple months into me working with SRNA and if you don't mind me saying you had talked about just your struggles with just being in a more rural location and getting proper support in that way. And I wanted to pick your brain a little bit on that because I do know that there are community members that we have both in the US and outside of the US that are in more rural areas. And I guess if you had any advice to give to people that are in a similar situation or trying to seek support and maybe having difficulty, can you just speak to your experience on what helped you and resources you were able to find and if you had any advice?

[00:17:20] **Sutxwaan / Nancy J. Furlow:** Sure. When I was first diagnosed or getting symptoms with MOG and ADEM, I was told at ER, I start going repeatedly that I was making it up. And so, as I was losing my ability to even sit in the wheelchair in the waiting room of the ER and I was literally collapsing in there. I later found out they just left me there because MyChart said I was making up symptoms. And so, one thing I've had to learn is to really advocate for myself, really, really educate myself about ADEM and MOG and optic neuritis and understand what's happening to me. I have printouts now that I take to the hospital. As I mentioned earlier, I have a MOG team and they all have printouts, digital and paper ones so that if anything happens, there's these handouts.

[00:18:35] And usually if I have to seek medical care, the providers don't know what MOG is or ADEM and they say, well, what is that? I never heard of that before. And so even though I'm there to get medical assistance, I'm in the position of having to educate. Even in January, I had an IV Port put in and the operating room nurses, the anesthesiologists and the doctor in my pre-op appointment asked me to bring those papers because they didn't know what it was, and they were a little bit afraid of working on me. So, I'm fortunate, I'm a little bit different than some people because I have to get health care through an Indian health service system somewhere. And sometimes there are - like I mentioned earlier in Sitka where I live, we have a hospital, but we have no specialist. They're a two-and-a-half-hour jet ride away, which is where I am right now in Anchorage. And even when I relapsed three weeks ago, it was hard to reach neurology here in Anchorage where my neurologists are and let them know.

[00:20:07] It's important just to understand what's happening to you and then to advocate and not give up. Sometimes, especially in rural areas, you have to just educate, educate, educate and it's really important to not be discouraged about that if you have to keep going and going and going and reaching out. And I'm always asking people like when I asked you, I asked -- I also do things with the MOG project. I'm always asking them, anybody that has ADEM or MOG about how do you do this or how do you do that. I learned from them.

There are some online groups through Facebook, private groups that are run by medical professionals. So, I trust what's happening in there and I reach out to them, but it's always learning, learning, and advocating and not giving up. In rural areas, it's just you have to be persistent that way.

[00:21:28] **Skye Corken:** Thank you for speaking to that. I'm also from a rural area. So that's obviously a topic that's near and dear to my heart. So, I appreciate you speaking to that and giving a little bit of insight into your personal experience. Adam and Graeme -

[00:21:45] **Sutxwaan / Nancy J. Furlow:** Also, our specialists aren't like here, like where we live, so we have to find them, and I am not beyond getting rid of somebody and getting somebody else. If somebody doesn't treat me in the way or understand what I'm going through and have the expertise. If I can, I will change.

[00:22:12] **Skye Corken:** That's a great point. It's important to have a medical professional team and professionals around you that you align with very much especially for something just as serious as this and it can just make a huge difference in your entire experience. So definitely getting the right people and not being afraid to make that switch.

[00:22:34] **Sutxwaan / Nancy J. Furlow:** Exactly. Especially like with ADEM, it's like, no.

[00:22:39] **Skye Corken:** Adam or Graeme, did you want to speak to anything about advocating? I know Adam, you had mentioned a lot about mental health and how big that's been for you as well. So, anything about ADEM you want to speak to?

[00:22:56] **Adam O'Connor:** I agree. I think having the appropriate medical team that has knowledge of rare issues such as these is important. But additionally, I think nonmedical teams, the people that surround you, the people that support you, as I mentioned in mental health, I have a therapist that has been wonderful. And Graeme, you mentioned have fears of relapse. That's one of those things I think that - it's been 10 years. But I think that at a certain point, I just had to let that go because I'm not going to live my life afraid of another super rare occurrence of something setting in. And so, I just go about my day.

[00:23:33] During COVID, I definitely messed up and stayed home and did everything I could to protect myself because who knows we were all dealing with an issue that was unexpected and unknown. I took precautions there. But this was for me an experience that was life changing and impacted everything that I did and everything that I do going forward and my considerations for everything in the future. I'm not going to let it stop me from doing anything, it's just something that is on my mind and while it may have been something I talked about with a lot of people for a long time, I told my story to many people. It's not how I identify now.

[00:24:11] ADEM is not who I am. It's something that I experienced and it's something that who knows what will happen in the future. But for the time being, I'm just me and I do the best that I can and Nancy, like you said, surrounding yourself with people who know your past and are aware to it. And if anything, odd may happen, just like, a first onset of ADEM for some random stranger, it's something that you should be aware to but it's not something that I'll let drive my fears in life. It's all I got.

[00:24:44] **Skye Corken:** Thank you, Adam. Graeme, anything to add on that?

[00:24:51] **Graeme Mackenzie:** Yeah, I feel with the care I got at Foothills. It's a teaching hospital. So, the main neurologist rotated every week and I saw seven different neurologists. I don't remember most of them because I wasn't really coherent. And once I was at the roundtable discussion for the Zoom meeting for Alberta Neurologists and they talked about me for their meeting and they didn't figure out the MOG until 10

months later, a thing. I feel pretty lucky that I ended up with this large group of people that really put a lot of thought into me. So, I felt very fortunate, and I was lucky I didn't have to do a lot of self-advocating.

[00:25:48] And at the beginning when ADEM struck, it was 10 days after I passed out, well 10 days after the vaccine I passed out, woke up, got an ambulance ride to the hospital. Five days after a couple trips to ER, I was in Foothills and then 10 days I don't remember. And everybody there was really good, and my wife has been a rock. She's been this pillar that supported me and it's two years in and I am opening up a little bit more on the social aspect and talking to people. But as Adam said, as soon as somebody asks about it's a five-minute story. I talk about it and I'm looking forward to the day when that isn't my main topic of conversation.

[00:26:45] **Skye Corken:** Thank you, Graeme.

[00:26:48] **Adam O'Connor:** Actually, if you won't mind, if I could add in really quick. None of us have gone through any of this alone. It was the thing, whether it's medical professionals or people that we care about and people that support and love us or SRNA, it's remarkable to meet new people such as yourselves that have gone through similar circumstances and these incredible things. But nobody's alone in this and nobody's alone really in anything. And I know that for myself, getting the help to come to terms with that was really important. But I was very fortunate. A lot of good people in my life helping to lift me up, and I would hope that there's not anybody out there that feels alone in this experience because there's a whole wealth of resources for anybody. And I wouldn't want anyone to feel hopeless because there's certainly times all of us have. So, it's not a permanent condition.

[00:27:42] **Skye Corken:** Thank you for saying that. Very well said, Adam. I want to jump into my next question and Adam, you touched on this very beautifully just recently. And if there's anything you want to add to it, please hop in. But I really do want to talk to each of you about personal identity because that is a big thing with a lot of our community members. And I'm just curious how you view your diagnosis in terms of your own personal identity. For some people, it's very interconnected, for others, Adam like you said, it does not define you. So, I think it's different for everybody. And I'm just curious what each of your own perspectives are. So, Adam you answered this a little bit and feel free to hop in and add more if you'd like. But Nancy or Graeme, do you want to start with this one if you're comfortable sharing?

[00:28:41] **Graeme Mackenzie:** I feel like I'm just starting the transition from being Graeme, the MOG guy to being Graeme, the rider or the skier, worker, parent, husband. For a year, it took over my life and that's all I could talk about. And now in second year in, it doesn't come up as much and it's still the little dark cloud over the shoulder lurking, but it's not as dominant and doesn't cast as big a shadow. So, it's working through it and that's my catchphrase but just being stubbornly active and doing something every day, even if you don't feel like it, five minutes in, you're good and then you're going and everything's okay and it really helps to keep things rolling along and not getting stagnant. I think I'm done.

[00:29:47] **Skye Corken:** Great. Nancy, do you want to go ahead?

[00:29:51] **Sutxwaan / Nancy J. Furlow:** Sure. I have a piano background, so I think about it in chords. Like there's melodies that have a - melody can have a single, melodic line, but chords are multiple notes. And for me, that's the way it is, I unlike Adam and Graeme, I'm not stable yet. So, I have periods where I go back to having to use a walker or a wheelchair and Graeme, if I was like you and I push myself physically, which I have done, I may set myself back weeks or months. So, I have to find this moving sweet spot all the time.

[00:30:36] **Sutxwaan / Nancy J. Furlow:** Yeah. And it's not a stable sweet spot. I mean, it's moving all the

time. So, it's finding that where that is pushing hard as much as I can without sending myself into a relapse. But not doing the opposite of just saying, oh, I can't do things and you learn to live your life. So, I've learned to live my life with ADEM and MOG and optic neuritis always right there. And I've had probably at least eight or 10 relapses in the last year and a half. But like Graeme said, so I don't feel like they're a dark cloud. They're just there. They're part of that chord. That's my life. And it's possible that I may never fully gain all my ability in my legs to do what they used to do. And that's okay. There's been periods where it wasn't and you mourn that, you mourn who you were and what you could do. And that's okay too. And I have to admit there's days I get scared, there's days I'm frustrated. I want to do stuff and my body's like, no can't do that or, I have to do stuff in little bursts of activity so I can do a burst of activity and then I have to rest or take a short nap and I can do a burst of activity and a rest or a nap. And that's okay. That's who I am now.

[00:32:25] And I think both Adam and Graeme said we're all lucky to be alive. I mean, all of us almost died from ADEM and I had my will ready. I was saying my goodbyes and that I'm here today is just like wonderful, like I was saying before we went live, I'm sitting here looking at these beautiful mountains in Alaska right now and being with all of you and that's incredible and we have this new community. It's not like we go through this alone, for those of - I always try to let people know because I don't want anybody to go through this alone because they're such amazing people to support us and guide us and answer our questions and be there with us when we're scared or when we're celebrating, like when I have done some long walks, like, everybody in physical therapy was clapping for me. It's amazing. So, you just learn to accept. I mean, we can't escape it. We can't escape this new us and we might struggle with it and fight with it for a while, but, ultimately - well, for me anyway, because I'm not stable yet, I've just learned to accept it and it's like those chords. It's just one part of my life along with other parts that I love and care about.

[00:34:11] **Skye Corken:** That's great. Thank you. That was all very beautifully said. Adam, did you want to add on to anything that you mentioned earlier about this?

[00:34:20] **Adam O'Connor:** Right. To me, it was a horrendous, it was a speed bump, and it was an experience in life, and it was something that we all still suffer the long-lasting effects of. But to be honest, it really helped amplify my empathy for other people for kindness, I want to help people that might be going through the troubling times of something like ADEM or maybe it's something else medically, not related to that, but we all know how challenging it is. And Graeme, you said a few times that, your stubbornness probably helped you. And I know for myself that was certainly the fact. I remember doing physical therapy one time and going home and I just finished using - I was between a wheelchair. I just got into using a walker and I went home, and I thought, well, a lawnmower is similar to a walker.

[00:35:14] So I mowed my whole lawn, and I went to physical therapy the next day and I told my PT, and she was like, "You did what?" And I was like, "Yeah, I mowed my lawn." And she's like, "You mowed your whole lawn?" I was like, "Yeah, I just went out there and I could lean on it, and it was like a walker." And she's like, "That's not like a walker." But I was like, "I'm going to try to get back to as normal as I can." And that's just the attitude that I had. And so, I have always wanted to try and tell people lean into the optimism, try, and do what you can, and you're going to do the best you can anyway. And like I said, none of us are separate individuals. This is all an evolution of life anyway. We're going to be better people and changing as people. And if this experience helped me to be a kinder person and a more caring person, the process sucked but there are things that are a happy byproduct.

[00:36:03] **Graeme Mackenzie:** The lawnmower is good incentive to not fall down.

[00:36:06] **Adam O'Connor:** Yeah, it was. It was not the best idea, but I just did it.

[00:36:10] **Graeme Mackenzie:** I remember celebrating my first lap around the unit with a walker, like the four-footed walker. We had to pick it up, put it down, pick it up, put it down and I finally made one full lap and high fives.

[00:36:27] **Sutxwaan / Nancy J. Furlow:** Or walking between the parallel bars and - actually, like we had parallel bars, it's like walking between the parallel bars, it's like my legs are moving. This is so - I mean, you get so appreciative of your legs.

[00:36:44] **Graeme Mackenzie:** The Foothills had a fall arrest harness with a lanyard and a track on the ceiling hallway length and basically take a step, fall down, try to stand up, get help, take a step, fall down into the harness and you don't hit the ground but you fall into the harness and it was a week before I could - probably a full week before I could go from one end to the other. Just those celebrate all the baby steps.

[00:37:13] **Adam O'Connor:** Humans are resilient and I'm a basketball player and so one of my goals long term was to get back to playing basketball. And I thought I don't care if I crump on the floor a couple of times, I'm going to try and do this. And I play regularly now and it's nothing short of a miracle. I couldn't move anything below my shoulders, when I first woke up from this medically induced coma and now, I'm able to go out and play basketball. It's amazing.

[00:37:41] **Graeme Mackenzie:** So just keep slogging along.

[00:37:48] **Skye Corken:** Well, thank you all for sharing a little bit. We have a few minutes left. So, I do want to go ahead and open it up to the audience. If anybody watching has any questions for Nancy, Adam, or Graeme, go ahead. Like I said, at the beginning, you can put those in the Q&A chat, and we'll try and get to those in the last few minutes. But while we're waiting for those to come in, I did want to ask one question and I think it'll be really interesting just to hear each of your perspectives because like I said, you're all in different phases in terms of your diagnosis journey and it goes back to your current support group network or your support network. And you had each talked about this a little bit, but what does your current support network look like? Is it an area that you feel at this moment in time still needs improvement? Are you pretty happy with it? Just wanted to get your own individual experiences on this as well. So, whoever wants to tackle that one first? And like I said, we will take questions as they come in. So don't be afraid to hop in everybody and put in questions in the chat for our speakers.

[00:39:05] **Adam O'Connor:** I'll hop in. From the very beginning from when I was first taken to the hospital before they even discovered it was ADEM, I felt like I was living in the old country because I would have friends and acquaintances and family that would drop things off at my house. Like my wife would come home from the hospital from being with me and there would be casseroles and gift baskets and cards and all posters and just stuff on our front porch and just everyone was so supportive and caring. And so, from the very beginning, I felt very fortunate to have people in my corner. And like I said, my medical team at the hospital here was incredible and PT and OT and my therapist. I mean, friends, family, everybody has been wonderful and every time I - even still when I bring my experience up, everybody wants to lend support and they're happy that I'm able to rebound as I have. And so, I'm able to lean into them when I need them. And I truly believe that it's been a huge difference maker for me because all that support and outpouring of care and love really, really touched me in special ways.

[00:40:26] **Sutxwaan / Nancy J. Furlow:** And like I said earlier - oh, sorry Graeme.

[00:40:29] **Graeme Mackenzie:** After you.



[00:40:31] **Sutxwaan / Nancy J. Furlow:** Like I said earlier, I have MOG with ADEM and optic neuritis, so I call them my MOG team. So, my daughter who lives here in Anchorage, which again is a two-and-a-half-hour plane ride from the small island community where I live in Sitka. She is my medical power of attorney. So, she makes all medical decisions for me when I'm unable to, but I need people locally. So, I have a group of people that I have trained to understand my symptoms and I text them and put them on a soft alert. So, they're my first line of outreach, put them on a soft alert if something's happening. Again, I'm not fully stable yet. And then if it becomes serious, I put them on a hard alert and that means they need to check in on me in case I become unconscious or really unable to respond. And if I don't respond, of course, they send someone to my home and my daughter begins to make - on a hard alert, she begins to make medical decisions for me.

[00:41:48] Then, locally, of course, have to go into the ER. Like Adam said, I feel really grateful for the medical teams that I have usually unless I have to go to the ER, which is hit or miss where I live. Sometimes they can be good and sometimes it can be a little bit on the nightmarish side where they are not understanding, they don't want to listen. They don't take my symptoms seriously and that's where someone from my MOG team comes with me and advocates for me if I'm unable to do that myself. And then I have physical therapists. I have occupational therapists, speech therapists that work with me. I do pool therapy. So, I'm able to get in the pool and move a lot better than I can out of the water. And my neurologists are here in Anchorage, and they periodically come to Sitka, or I see them up here. And because I have MOG with ADEM and optic neuritis, they outreach to some of the MOG researchers including the Mayo Clinic to sometimes consult with as this or that is happening with me.

[00:43:13] Plus, just a group of friends who are amazing. I mean, some of my friends have like - I mean, I knew they were good friends, but they really have shined, and it's been really neat to see how they've stepped up and are so supportive and caring. And like Adam said, brought me stuff and do things for me. Even one of my physical therapists brings dinner one night a week it's incredible. It makes you feel so loved and cared about as you're going through this journey that is like shocking when it first begins. But then you realize, it's okay. I'm not alone. There are people that will help me, and we will get through this all together.

[00:44:08] **Graeme Mackenzie:** Nice. For me, when I went into hospital, it was the COVID vaccine that was my trigger. So, it was right when shutdowns were happening and everything was going into lockdown. Carrie was the only one who was allowed to come in to see me at the hospital. But she got a lot of support, meals were dropped off and food and snacks and she got rides and people helping out. It was a really good village that helped her help me. And then once I got out of the hospital, it was pretty much Carrie like I was able to walk and move but just not all day, all the time and not work capacity type thing. So, it was - the neurologists are great. They listen and do what they have to do. But really my whole support network is my wife, Carrie. So as much as the village helps her, they help me, which is really nice.

[00:45:21] **Sutxwaan / Nancy J. Furlow:** And I just want to briefly say I live alone. So that's why I created a MOG team because I live alone by myself. So, if it's something happened and I was not conscious, for example, I need somebody to know that something's going on with me.

[00:45:42] **Graeme Mackenzie:** So, I've got Carrie and two kids in the house. So, a lot of time to lay down by myself.

[00:45:51] **Adam O'Connor:** It's just me and my dog. So, fingers crossed, don't know what to do if something goes wrong.

[00:45:57] **Graeme Mackenzie:** Dogs will probably let people know.

[00:46:00] **Sutxwaan / Nancy J. Furlow:** Yeah, dogs are smart that way, they would let somebody know.

[00:46:05] **Skye Corken:** Yeah, they are. Oh, great. So, I don't see any questions coming in, but that's okay. So, we can go ahead and wrap it up here because like I said, I want to be respectful of your guys' time. I just want to give a big thank you to you Nancy, Adam, Graeme for coming on here and taking the time out of your day to share your experiences. It is so important, and it really does make a big impact on this very special community. So, any time we can share with each other, it's making a difference, even if it's just with one person, it really is so valuable. So, thank you so much to the three of you for coming on here today and thank you to our audience for watching as well.