Mental Health and NMOSD

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[00:00:02] **Intro:** "ABCs of NMOSD" is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder or NMOSD; a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. "ABCs of NMOSD" podcast series is hosted by SRNA, the Siegel Rare Neuroimmune Association and in collaboration with the Sumaira Foundation for NMO and Guthy-Jackson Charitable Foundation. This education series is made possible through a patient education grant from Horizon Therapeutics.

[00:00:59] **Krissy Dilger:** Hello everyone and welcome to the "ABCs of NMOSD" podcast series. Today's podcast is titled "Mental health and NMOSD." "ABCs of NMOSD" is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder. My name is Krissy Dilger, and I moderated this podcast. "ABCs of NMOSD" is made possible through a patient education grant from Horizon Therapeutics. Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:01:53] For today's podcast, we are pleased to be joined by Dr. Mary Rensel and Dr. Amy Sullivan. Mary Rensel, MD is an Assistant Professor of Medicine at the Cleveland Clinic Learner College of Medicine and Director of Pediatric Multiple Sclerosis and Wellness at the Mellen Center of the Cleveland Clinic. She has graduated from the Medical College of Ohio and completed her neurology and neuroimmunology fellowship training at the Cleveland Clinic. She is boarded in neurology and integrative medicine and is a fellow of the American Academy of Neurology. Dr. Rensel's work has focused on adult and pediatric multiple sclerosis, brain health, and integrative medicine.

[00:02:37] Her work in academic medicine often intersects with professional wellbeing, wellness advocacy, innovation, and strategic initiatives. She serves on the steering committee of the National Network of Pediatric MS Centers. She is a Best Doctor of Cleveland since 2010 for the Cleveland Magazine. She has served as President of the Women's Professional Staff Association of the Cleveland Clinic and sits on multiple boards, including the Ohio National Multiple Sclerosis Society. She is active as a coach, mentor, scientific reviewer, clinical researcher, activity director, entrepreneur, and national speaker.

[00:03:20] She has also appeared on numerous media outlets including a spot on Good Morning America. Amy Sullivan, PsyD, ABPP is the Director of Behavioral Medicine and Research in the Mellen Center for MS, Director of the Neurological Institute Engagement and Wellbeing and is the Chair of the Institute's Diversity Leadership Development. Dr. Sullivan's work has focused on mental health and people with chronic diseases and their family members, as well as physician burnout and diversity empowerment. Her work in academic medicine intersects with teaching, mentoring, programmatic development, and strategic initiatives. She

is an expert in group dynamics and curriculum development as well as psychological factors impacting multiple sclerosis.

[00:04:07] Her most recent work has been in transforming clinical practice with telemedicine and COVID-related stress. She has over 100 media appearances and over 250 national and international talks. She has also contributed over 30 times to literature and book chapters. Dr. Sullivan is an invited member of a select group of wellness researchers through the National MS Society, and she and her research team were the recipients of the Robert J. Herndon Award for most outstanding IJMSC article. Dr. Sullivan was most recently the 2021 recipient of the School of Medicine Faculty Mentor of the Year award.

[00:04:51] She also received a scholarship and teaching award through the School of Medicine, and she was also the recipient of the outstanding early career psychologist award by the Cleveland Psychological Association. She was honored also to receive the extraordinary graduate of St. Bonaventure University award and named a woman of outstanding leadership and health care. In addition to her clinical and teaching role, she is passionate about physician self-care, burnout, diversity, and leadership and psychological health, and is the Director of the Neurological Institute Engagement and Wellbeing Office, where she works to improve physician wellbeing in her institute.

[00:05:32] Welcome and thank you both for joining us today. We're excited to have this topic to give to our community. So, can you both just begin by explaining what the goal of mental health care is and how each of you use that in your practices?

[00:05:51] **Dr. Mary Rensel:** Sure. Dr. Sullivan?

[00:05:53] **Dr. Amy Sullivan:** Sure. I'd love to start. So as a behavioral health psychologist, I think what's important to me is that I see patients who are adjusting to a chronic disease or adjusting to a change of function. Well, disease tends to be very difficult on the person. It steals so much from the individual. My job is to help the person adjust and adapt and to get some joy back in their lives. And so, from my perspective it's a vital part of the comprehensive care of an individual with a chronic disease.

[00:06:29] **Dr. Mary Rensel:** Yeah. And I am a neuroimmunologist. And so, from my perspective, I see a mood disorder can change how people feel throughout their day. We in medicine we call that quality of life, but just like how great are the days like Dr. Sullivan's mentioning like how joyful do they feel like? How do their days go? And we can measure that with something called quality of life measurements and we've seen that mental health can indeed affect those. So, if a person is feeling anxious or feeling sad or feeling concerned or they're still adjusting to a chronic disease then we can see that their quality of life is less. So, we do want to always screen in our neurologic here, because we can see that indeed mood disorders can affect how a person feels throughout their day.

[00:07:15] **Dr. Amy Sullivan:** Yeah, and I think that that's an important point that Dr. Rensel is bringing up. So, one of the things that we do here at the Mellen Center, and we've done this for the past 12 years since I've been here, we've put into the neurology appointments, depression, or mood screening tools. And what happens is the patient comes in and either via their smartphone or a tab or with an individual, they fill out a mood questionnaire and on that mood questionnaire, they're identifying how they're feeling throughout the course of the past couple of weeks.

[00:07:48] And if the individual is feeling depressed or if they're noting anxiety, the neurologist or the neurology team has the opportunity to refer to our practice. And so, it's a beautiful consultation model with collaborative care here at the Mellen Center which I appreciate so much, because we work so closely together that we're

able to touch base about the patients or run down and meet the person in the office. We call that a warm handoff. So, anything that we can do to help the neurology team and the patient is a goal for us.

[00:08:22] **Dr. Mary Rensel:** I agree. And we know that if we can instruct the patient or the caregiver, but a few daily tools by knowing that indeed they do have a mood disorder and that's why they're saying they feel bad throughout the day. If we can treat that, just like we would, if they said they stub their toe or their hand hurt, we would address that. If they're saying I feel down or tired or fatigued, we always want to look for a mood disorder, because it certainly can affect how a person feels throughout their day.

[00:08:50] **Dr. Amy Sullivan:** Yeah, yeah. I think that brings up another good point, which is the high prevalence rates of mood disorders in people who have chronic diseases. And so, it's really important for us to recognize that it's not only an adjustment to a disease, although that can be part of why an individual is having higher prevalence of mood symptoms, but there's also biological reasons why one may have increased symptoms. There are sometimes reactions to medications. The reason is someone might have an increase in mood symptoms. So, there's a variety of reasons why somebody may have an increase in mood symptoms. And it's very important for us just to be aware of the higher prevalence and to assess for that.

[00:09:31] **Dr. Mary Rensel:** Yeah, the neat thing is, you know, some of the tools that can be learned and polished and practiced can actually build something called resiliency so that folks have a toolkit that if they're having a bad day, they're feeling down about their disease or having to take a medication that they've come into behavioral medicine they've learned they have this toolkit a toolbox full of things that they stand ready to support them throughout their day and that has been shown to lessen how often a person does feel depressed or tired or even their pain level. So, we can have a lot of interaction and we can actually enhance their quality of life, how well they feel throughout their day by teaching them some of these tools. So, it's really neat to me to see when I do refer someone to our behavioral medicine team, and they come back feeling way more empowered. They feel like they know what to do when they're having certain thoughts or certain feelings and they know exactly how to improve their day and brighten their day. Which is just such a gift.

[00:10:33] **Dr. Amy Sullivan:** Yeah, I agree. There're so many reasons why you would want to refer somebody from the psychological perspective from the wellbeing perspective and of course from the physical perspective. I think we were very lucky to be able to treat all aspects of the human being.

[00:10:50] **Dr. Mary Rensel:** Absolutely. Yeah. And I think the other thing is that we know that certain things correlate especially pain. So, folks that we know living with an NMOSD sometimes they've had a lesion in the brain or the spinal cord and leaves them with high degrees of pain or it may leave them with a symptom called tonic spasms and those are very painful. I've seen people just crying in my office when they go through those and it's horrible to experience. And if we can treat the symptom that's causing their pain sometimes that will indeed help the mood disorder. But even reverse is true. So, if they our folks go work with our behavioral medicine team and then come back and they say even my pain is better and my energy is better, and I know how to handle when those symptoms come back or the pain from the spinal cord lesion is bad. I have some new tools beyond a pill which is really empowering for the patient.

[00:11:44] **Dr. Amy Sullivan:** Yeah. Dr. Rensel, could you talk a little bit about your practice and when you send somebody up to see us in behavioral medicine, why would you send somebody, what symptoms are you seeing and what does that referral process look like?

[00:12:00] **Dr. Mary Rensel:** Sure. So, I have the honor of meeting people right at their first symptom or sometimes I meet people in the middle of their course of living with NMOSD. And I treat kids and teens and adults with this disease. So, it can be quite impactful to say the least of what symptoms may fill their days

or how they may feel. Thank goodness. It's such a new day for NMOSD, because there are new medications and there's three FDA approved medications and so folks now have the ability to actually chose and you use medications have been proven to help NMOSD.

[00:12:34] So it is a brighter day, because I have so many treatment options to discuss and treatment plans. But like even just yesterday I was seeing someone, and we diagnosed her, and I said, and I'm going to refer you to help behavioral medicine, health psychology and she said, "Why?" And I said, "Because like you thought you were going down this road and now, you're on this road and we call that adjustment. And so, you'll be adjusting to hearing that you're living with this new condition." She said, "I feel okay." And I said, "That's great." I just want them to just meet with you and review what you do to manage your thoughts, your stress, because we know that influences the health of the immune system and the state of the immune system.

[00:13:15] So we've all been in the where we're run down and we get colds more often or we're run down, because we're caring for a family member or busy at work and we feel exhausted and then we get we get more illness. So, we know the immune system can be affected by our behaviors and our stress and how we care for ourselves? So, 100% I refer people when I give them the diagnosis and then some other reasons I may is like, just so we were discussing earlier that maybe someone's reporting a lot of pain or a lot of tiredness. We want to also have the behavioral medicine team help us tease through all of that. Is there mood disorder under this?

[00:13:55] We do the evaluations like Dr. Sullivan was mentioning that the patients will come in and answer questionnaire. So, we have a number and an evaluation. You know how anxious they may feel or how depressed or concerned or stressed they may feel, which is very helpful, but sometimes it takes more. It takes a discussion with behavioral medicine to sit and go through exactly what's going on and how they're feeling in more detail. So, I would say I refer people for many reasons. One gamut is their first diagnose, number 2 is they're having a plethora of symptoms and we're trying to tease through the symptoms, is there a mood disorder in the middle of this?

[00:14:29] And then we have the extreme needs, or someone comes to me, and they say feeling really down, I don't have much pleasure in my day. And then we have to ask very important question, very pointed questions that are very hard to ask, because they're very personal, but we need to get to it. We said, have you ever thought of hurting yourself? How sad do you feel? Do you have anyone that lives with you? So, we need to kind of check in are you suicidal? Do you have a plan? You feel like hurting anyone else?

[00:14:56] These are very serious questions, and this is like what Dr. Sullivan had referred to earlier, that this is something we do a lot is called a warm handoff that we will call the behavioral medicine team, or we will call some of our teams we have in house in our hospital system and say, you know, we have somebody here, they're actively suicidal. We need right away get them care immediately. So, so I, you know, there's a there's a gamut of reasons that I would send somebody to behavioral medicine or health psychology, but those are the three main areas newly diagnosed suffering with a lot of symptoms and we're trying to tease out our very active mental health disorders. Yeah, Dr. Sullivan, when do you want us to refer people to you? What would be helpful to your team?

[00:15:43] **Dr. Amy Sullivan:** Well, I think first and foremost, if you ever feel like somebody's in danger, that's incredibly important to send somebody to us or to have us come and evaluate the person. The people can become very down and depressed, and I think it's very important that we take care of them during their crisis or their need. I also think what we've seen recently, just in the media is that people don't always reach out for help. And so, I think it's important for us to establish these relationships with our patients up front, just as

you were speaking about Dr. Menzel, when the patient is newly diagnosed and they have that ability to see somebody on our team from a behavioral medicine perspective, just so that we can put our eyes on them and let them know that we care.

[00:16:31] It's a different type of process that occurs in our office than is in your office. Many times, in the neurologist's office, you're talking about a lot of symptoms. So, mood could be one of the symptoms, but there's a lot of other symptoms that are occurring that you need to address. So, what we find up here is we're able to talk about whatever it is that's on the person's heart. And if the person is struggling, we work hard to create that relationship first and foremost, and then allow that person to have a safe space to talk with us about their feelings. This is a very objective place and the individual feel safe. They're able to share their vulnerabilities.

[00:17:11] It's such a pleasure for us to be able to do this work with people. They tell us things that they likely don't even share with their significant others. So, we feel like we're in a very privileged role and we don't take that lightly. The other things that we do very well is we've created a stress management protocol. So, you were talking earlier about the impact of stress on the body and that is absolutely right. So, we think about the sympathetic nervous system. So, the sympathetic nervous system is this system that it turns on when the body or the person feels threatened and they're trying to survive essentially. So, it's evolutionary for the human being and when it was very helpful, was back in the days of the hunters and gatherers when tigers or something dangerous was chasing somebody. So, we turned on the sympathetic nervous system and we were able to escape from the danger.

[00:18:08] Well, what's happened over time is that we have now turned on our sympathetic nervous system when we're driving in a car when we're sitting in a meeting, when we're at work when we're paying bills and we're at the grocery store and all of these kind of mundane daily types of chores or activities. The sympathetic nervous system is turned on and that wreaks havoc on the body from a physiological and a psychological perspective. And so, one of the things that we think is very important for us to teach our patients is how to shut down the sympathetic nervous system and turn on the parasympathetic nervous system so that when we're able to turn on the parasympathetic nervous system, we're able to turn on the body's ability to rest, rejuvenate and recover.

[00:18:53] And when that's turned on, the sympathetic nervous system cannot be turned on. They don't both work together. One works and the other one is off. And so, we've created a stress management protocol. It's a four-session stress management protocol where we teach individuals first, we educate them about our nervous system and why it's important to shut down that sympathetic nervous system response and then we help people to get into that rest, relax, rejuvenate state where they're wearing a biofeedback tool and we're able to measure the body's physiological response to stress management and stress.

[00:19:28] So for example, if somebody had the biofeedback tool on and they were talking about a very stressful situation at work or at home or they're scared about their disease, change of functioning, whatever it may be. What we see are that the biometrics are reading as if somebody is in a naturally stressed-out state, their heart rate increases, their breaths permanent increase. We're looking at their saturated oxygen that's usually decreasing. But when we teach somebody how to manage their stress and we do this in a number of different ways, we see the exact opposite. So, what we see there is the heart rate decreases, the breast permanent decrease and the saturated oxygen increases.

[00:20:13] And so we're able to show people how they're responding to managing stress. And the cool thing about this protocol is not only that we can share the data with individuals so that they can see that within

session, but they're also turning off that sympathetic nervous system response. But it also is something that extends throughout time. So, if they continue to practice this outside of our office, people will get this biofeedback tool and be able to practice this outside of the office and they're able to keep their heart rate lower or bring their heart rate down or bring their breast permanent down. And it's a really neat thing to watch.

[00:20:50] Another part of the stress management protocol that I think is important is that we teach people skills that build off of each other. So, we teach in the first session like I shared about the education and then we teach people just a diaphragmatic breath. And diaphragmatic breath is really so very important. And it's kind of where we build all of our stress management tools, especially our breathing tools from. So, it's a very important skill for people to learn. And sometimes just that skill itself can take an entire session for us to teach, because people are naturally stressed and their body doesn't want to diaphragmatically breathe, it wants to breathe from the chest, and we build off of there and then the next session we're teaching people serial three breathing or circular breathing.

[00:21:33] And then the next session we're creating visualization where we actually ask people to use their five senses and tell us where the most relaxing places for them. So, we're creating a visualization script personalized for the individual. We move onto body scanning and then we move into mindfulness. And mindfulness is one of my absolute favorite tools to teach people. Mindfulness is about learning how to stay in the present moment instead of looking ahead into the future where there can be fear and anxiety or looking into the past where there can be regret, remorse, and depression. And so, our protocol teaches people these skills and tailors them to the individual need and we figure out how a person might use these particular skills in different stressful situations or just in everyday life. And so, we're really proud of that protocol and we have data that shows that people are getting better with using that protocol.

[00:22:34] **Dr. Mary Rensel:** I've heard patients have gone through that and I'm just so appreciative of the skills. One funny one that comes to mind are the couple that that has spoken in some of your national meetings and there's something about washing your hands. Yes, tell us that story.

[00:22:47] **Dr. Amy Sullivan:** Yeah. So, one of the skills that I teach is called mindfulness-based therapy and one of the exercises that we do is about using your five senses. There are people that I've known for a very long time, and I was teaching the skill and I asked them to find some soap that is. So, the way I teach this is to find some soap where it turns from the thick gel into the suds as you put under the water. And so, you pump the soap out of the dispenser. It's a thick gel on your hands and I want people to feel that and feel what that feels like as if they've never experienced it before.

[00:23:35] And in this instance the soap became very sticky, and people aren't necessarily, they didn't know that, and I wouldn't either. If I hadn't done this experience with people, I wouldn't know either that the soap is very sticky. So, I remember the situation where we were doing this, and the soap became very sticky, and they were trying to describe it and they're like what is wrong with the soap? Why is the soap so sticky? Well then you put water in it and the soap completely changes in consistency. The smell changes and you learn how to teach different skills. So that's just one skill of mindfulness that I teach.

[00:24:11] Another is sipping tea. I think sipping tea is a very wonderful skill for people to do. So, it's using your five senses to sip the tea and to explain what that feels like and what that smells like and what does it taste like? What you hear when you're sipping the tea? Similarly, walking in snow or grass or just being outdoors is another way to be mindful. So, the idea here is pulling on your five senses so that you're in the present moment, you're in the here and now. And every time I've done this with somebody, I don't think in 12 years I've had anyone. This may be an exaggeration and maybe I'm just not remembering it correctly, but I

don't think I've ever had anyone who I've walked through one of these exercises that has been thinking about something else other than being in the present moment. And I think it's really important that we focus. not only as our patients, but as a society to be able to be in the present moment and not think about what we have to do five minutes from now or what might happen five years from now or what we regret that we didn't say or didn't do five minutes ago or five years ago. The gift is in the present.

[00:25:28] **Dr. Mary Rensel:** I love that. Yeah. And I think the funny thing was that then when the couple was talking about like when they're upset, they're like go wash your hands. Because it helps them to settle down. That was the tool they used to settle down.

[00:25:41] **Dr. Amy Sullivan:** Yeah. And they also have this biofeedback tool at their home. And so, when they're particularly stressed so the individual that has MS, he gets spastic. And so, what we're able to do is we've taught them ways to use the relaxation skills by way of him-- He's an engineer. So, he likes data. So, we've taught him how to use the biofeedback tool to shut down or even slowdown that sympathetic nervous system response so that he is able to then regain control of his body. So, it's a really special skill and it works well with my patients. And I'm really glad that we have data that supports, that is working well for them as well.

[00:26:29] **Dr. Mary Rensel:** Yeah, I love those stories. That's great. I was looking at some of the literature comparing MS and NMO. And it looks like some of the literature suggests that folks living with NMOSD have even a lower quality of life as compared to MS. Have you seen in your practice that you have to do anything differently because of the different disease states?

[00:26:51] **Dr. Amy Sullivan:** So, for us it's not necessarily the disease, it's the symptoms. So, we look at people based on needs. So, whatever their functioning needs are, or their mood needs, they help us to set their treatment goals. So, I would say, no, we don't. I don't look at it based on disease; I look at it based on what the needs are for the patient. And from my perspective, there has to be dual participation in behavioral medicine therapy, I'm speaking. So really in any type of therapy, right? So dual participation is I may be motivated as the psychologist for the person to get better, but the person may not be motivated or may not be ready.

[00:27:37] And so I always say to my patients when they come in and perhaps their caregivers with them or their significant other, whoever May be with them, that I can drive the horse to the wild, but I can't make it drink. And I think that that's really important for our patients to hear, because sometimes our patients just are not ready. And so, we have to make sure that this is largely motivated by the individual that's in treatment,

[00:28:03] **Dr. Mary Rensel:** Yeah, true. Yeah, that makes me think of bias. So, when I introduced this to some people in the clinic, they said no, no, I'm fine. I don't need that. And then usually if I say think about it and I thought I was going on a trip to Holland and the plane landed and I was in France and I'm still on a trip, but it's just not what I expected. And I have to shift my thinking and my plans, and I wasn't ready, and I wasn't prepared for this. So that's what we try to change the perception a little bit that these are tools like you had said that they're long-lasting tools. Once you learn them, you have them forever. That just makes some practice. Yeah. And when we talk about bias, some people will say, well this is more for women, this is men, this is certain age that's better than do you think that there's a certain population that's more receptive or was it more of an individual state?

[00:28:55] **Dr. Amy Sullivan:** Yeah. So, I would have said that 10 years ago. I think we've made significant progress in terms of normalizing mental health in the past decade. So, in the past five years, the population that we've focused heavily on is our male population and I think that there are unique needs with our men. So, when we think about men's value, this is a generalization. So, this is not all men, but many men's value

system is based on what they can do or their functions. So, their work, how much money do they bring home to their family, what kind of chores can they do around the house? How can they be helpful?

[00:29:37] Whereas women's value system can be also based around their work, but there's also this nurturing side to them. So, from a mental health perspective, men tend to do poorer with chronic disease, especially if they're leaving the workforce, if there's role reversal and they're going home and their significant others going to work, if there's loss of function so they can no longer do the duties that they had once performed for their house. And so, one of the things that we started to focus on was work around masculinity and what that means.

[00:30:12] And about five years ago, we had a fellow who was just exceptional, and he brought into our practice and created a group for men. And so, our groups are very unique at the Mellen Center. They're really special. They're all Zoom-based and people are able to zoom in from all over the state of Ohio, because our license is throughout the state of Ohio. And so, we've had all kinds of groups. And what we've noticed recently though is that our men's group is the most popular group that we have at Mellen Center.

[00:30:49] So we have a group of men that are so highly engaged with this group. We're always recruiting, and we are offering people spots in the group and once the group fills, we'll just break it off and do or I shouldn't say fills. Once the group is too large, we'll break it off and do two months groups, because it's such a popular group here at Mellen Center. And that is surprising to me, because I would have thought based on biases is that women do better with a process-oriented work. But in this case when you look at our group work, so we have groups that are all over the board, the men's group does better.

[00:31:30] **Dr. Mary Rensel:** That's amazing. Yeah. I love it. Yeah. I love that fellow years ago and you came up with that plan and then it lives on. I have heard from some of the patients that are in that group. They really do appreciate the long-lasting support and having people understand, because when they're in the lobby and NMOSD is just like MS. It's more generally female oriented. So, it's two thirds female compared to one third men. So, when they're waiting for the doctor, they're seeing people at groups or the walks or what have you a lot of the events. It's more women than men. So, most of the time they feel like this is not their disease or they don't really belong. And some of the patient support activities or even at their medical condition at their medical appointments. So that's wonderful that this group exists to support them.

[00:32:19] **Dr. Amy Sullivan:** Yeah. Another unique population that we serve are the caregivers. So, the caregivers are people loved ones of patients who are receiving care here. And I think that it's important to talk about them as well, because when we think about a chronic disease or any kind of disease, really, it doesn't just affect the person, it affects the entire family dynamic. And as we were talking about with our men's group, some of the things we talked about are role reversal. So, in some situations, there's a husband or a wife or a spouse who ends up going back to work and that wasn't their plan either. They wanted to stay home and take care of the children and there's this role reversal or there's a significant other who is now playing the role of a nurse.

[00:33:01] You can think about all kinds of different role reverse. And these are really important things to talk about. But we offer a caregiver support group again, throughout the state of Ohio for anybody who is the loved one or is caring for somebody with a chronic illness or disease, we offer them a space to talk about their own unique, because there's data out there that shows that the caregivers don't take care of themselves and it's like the analogy of the flight attendant. When the flight attendant comes on prior to the plane taking off and saying in the event of an emergency, if the action mass drops, it's important to put on your action

mass first before taking care of anybody else. And basically, I think that's a beautiful analogy for life. We have to take care of ourselves first before we can take care of anybody else, because we're no good if we're not functioning well or we're not healthy.

[00:33:55] **Dr. Mary Rensel:** So true. Yeah, absolutely. So true. I always when I'm in the visit with a patient or somebody living with NMOSD and their friend or caregiver next to them and I look at them and I asked them a question if I asked the caregiver question, they're surprised that I'm addressing them. But some of your sessions that you've had, some of your caregivers have explicitly said what it was like when they weren't addressed. And so that has helped me keep that strong part of my conversation with the patient and their caregiver and provide resources. Because the literature suggests absolutely that the stronger the caregiver, literally the longer the person lives living with a chronic disease and the quality of life improved.

[00:34:38] So for so many reasons we want to support the caregivers as well and same thing, just like you said, it's okay for them to take time. We have some caregivers that get out of the house and go meet with friends or go play cards with friends or head to the gym or have standard three hours here or there and get some help and get out of the house so that they can have their own life and speak with their own friends and not only be in the caregiver role. So that is important to take care of yourself and set boundaries about when you need a break or to rest and recharge. Super important.

[00:35:11] **Krissy Dilger:** Great. That was such an impactful and important conversation. We're really happy to have you both here to talk about this topic, because it isn't something that's always talked about. So, we're really grateful and hopefully we can continue this conversation in the future.

[00:35:31] **Dr. Mary Rensel:** Thank you for the opportunity.

[00:35:32] **Dr. Amy Sullivan:** Thank you so much. It was a pleasure being here.