

Psychosocial Aspects of NMOSD: Anxiety, Depression, and How to Cope

You can listen to the audio of this podcast at: <https://youtu.be/qMowquhBbls>

Intro: [00:00:00] ABCs of NMOSD is a 10-part 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, the Connor B. Judge Foundation and Guthy Jackson Charitable Foundation. This education series is made possible through a patient education grant from Viela Bio.

Krissy Dilger: [00:00:57] Welcome to the ABCs of NMOSD Podcast Series. Today's podcast is about Psychosocial Aspects of NMOSD: Anxiety, Depression, and How to Cope. My name is **Krissy Dilger** from the Siegel Rare Neuroimmune Association. ABCs of NMOSD is made possible through a patient education grant from Viela Bio. Viela Bio is dedicated to the development and commercialization of novel, life-changing medicines for patients with a wide range of auto-immune and severe inflammatory diseases. Their approach to drug discovery is aimed at providing targeted treatments for improved outcomes for the thousands of patients who have few or no therapeutic options. For additional information about Viela, please visit vielabio.com.

[00:01:50] For today's podcast, we are pleased to be joined by **Katherine Chapman**. **Katherine Chapman** received her Bachelor's Degree in Sociology and Master of Social Work at Louisiana State University. She received her board certification in 1998 and is a licensed clinical social worker. Katherine has been at the Multiple Sclerosis Program at UT Southwestern since September 2002.

[00:02:15] She works with a dynamic multi-disciplinary team in the CONQUER Clinic and the team at Children's Health Dallas, participating in research and patient care. She assists children and their families by locating resources, providing support and information. She serves as a therapist in the adult clinic, assisting people with MS, NMO and TM to manage depression, anxiety, insomnia, and general life stressors.

[00:02:43] Welcome, Katherine. Thank you for joining us. Can you just begin by explaining how NMOSD can affect a person's mental health, and why does NMOSD cause anxiety and depression in some patients?

Katherine Chapman: [00:02:58] Well, thanks so much for having me. We know that any new diagnosis like NMO can be very shocking and disruptive to individuals and their families. You know, everybody shares the impact. And then there's so many additional stressors that are put on people with their health and the unpredictability. It can be expensive. There's lots of decisions to be made. And then symptoms to deal with. It may not necessarily be visible like symptoms of pain. You know, and every family and person is going to react and adapt in their own way and in their own time.

[00:03:39] So please try to put down any expectations of how you think you or others should feel or think, and let yourself know that all feelings are okay, and you have a right to feel what you feel. And we don't know

exactly why. You know, it's a complex thing as far as depression goes, because there could be a biological basis, and we see this in MS.

[00:04:05] So I think it'd be fair to say that this could be the case for NMO too, and we don't have the research yet. But again, I think it's fair to say that there could be some interaction there. And then definitely people can have depression and anxiety as a reaction to having NMO. And that is entirely normal to just feel all kinds of emotions after a new diagnosis or a change in function.

[00:04:32] And some of those common reactions are anger, sadness, the anxiety, depression, and grief. And, you're right just to be like you're on an emotional roller coaster. That is totally normal.

Krissy Dilger: [00:04:49] Okay, thank you. I think that was a really good explanation. So the next question is, how can a person tell whether they are experiencing anxiety and/or depression? What are some common symptoms? I know you just mentioned grief and anger. But, I guess, how do you determine whether these are just normal emotions or something that's a little bit more serious?

Katherine Chapman: [00:05:18] Yes, yes. And sometimes it is challenging to figure out between those things. But, as far as depression goes, recognizing that, you know, you're looking at, if you're feeling a certain way for two weeks or more, you know, we all have our good days and bad days, you know, as far as our emotions go.

[00:05:38] But with depression, it really sticks around and you're feeling sad most days that could also look like irritability. And then the other hallmark of sadness is, or hallmark of depression is having little or no interest in doing things that you generally enjoy doing. So, if you, you know, had some hobbies or you hung out with some particular groups or friends and you just really don't want to do that, that might be a sign.

[00:06:08] And then other things that could be a depression with those two things is weight gain or loss, having trouble, sleeping, having difficulty making decisions, trouble with your concentration, feeling guilty or unworthy and then thoughts of death or suicide. So if you are having any of these, you know, difficult emotions, please, please reach out for help.

[00:06:37] We'll, we'll be talking about that. Talk to your family, your medical team, and if you're struggling, you know, if you are struggling with depression, you know, please reach out for help, cause the good news is that can be treated. You know, there are so many things that you can do to, and strategies to learn to deal with depression and anxiety. And for anxiety, which is also very challenging, you're having excessive worry. Like you can't control it. It's just worry, worrying all the time. Having a really hard time, relaxing, you know, feeling anxious and on edge. Or feeling scared, like something really bad's going to happen. And often anxiety and depression go alongside each other. So it's not unusual to have both.

Krissy Dilger: [00:07:27] Okay, great. Thank you. So for someone who is diagnosed with NMOSD and experiencing anxiety and / or depression for the first time, where is the best place to start for treatment? Would you recommend therapy, medication, self-coping strategies or anything else?

Katherine Chapman: [00:07:50] Okay, well, yes, all of those. I would start by talking with family or, you know, figure out who is your support network, especially newly diagnosed, you know, who are the people you can count on, who is going to be there for you?

[00:08:07] And try to find at least one friend or family member that you can count on, try building your support network, and please talk to the medical team. But therapy and exercise are a great place to start. And certainly medication can be very helpful in some cases. And you know, this is how this was described to me: if you

feel like you're in the ditch, the medication can be your tow truck to get you out of the ditch. And then you do therapy and exercise to help you stay on the road while you're learning new skills and ways to cope. And there are so many benefits to therapy. It can help people reduce stress, work through problems, understand their thoughts better, and just have someone to talk to. And that's objective and not in their close circle and improve coping skills.

Krissy Dilger: [00:09:02] Okay. Great. Thank you. So what are some of the most common coping strategies or coping skills for anxiety and depression that's caused by NMOSD?

Katherine Chapman: [00:09:15] Okay. Well, this is a great question. And, depending on the therapist or counselor that you see, you know, there is all kinds of different lines of therapy out there.

[00:09:27] But I would start with, focusing on wellness, that is very key and managing stress. And stress can be tied into so many symptoms too that doing the diaphragmatic breathing. You know, if you're not doing that, you know, try to take time in the day to do that. And I would encourage everybody to adopt some kind of guided meditation practice.

[00:09:51] One of my favorite apps is insight timer, and there are tons of free meditations on there to listen to. Exercise, journaling, that can really help you identify healthy and unhealthy patterns, help you with making decisions. Also being in nature. And another way to promote your wellness is that you need to protect your time.

[00:10:17] So you may need to say no to things, but that it's healthy to have boundaries and give yourself permission to say no. And a good rule of them is just give yourself at least 24 hours. So think about, is this something I want to do? And because this really is a time to prioritize what is important to me and start with small changes, but think about, is there anything I can cut back on or eliminate.

[00:10:44] You know activity, well, not activities, but maybe commitments that are really into, you know, trying to distinguish between those and what are the things I really want to be doing. And then of course, something that I start people off with usually is a self-care script. And thinking about what are the things, how do I want to feel? And then what are the things I can do to promote those feelings? So there's so many different things you can do, but we might want to feel energized or joyful or peaceful. And then think about well what are the things I can do to promote those feelings. That might be exercise. That might be eating nutritious food. It might be focusing on sleep, which I think is the foundation of our health, you making sure that that is in order.

[00:11:35] Also, you know, having alone time, having quality company, having time just to putter around or hobby time. You know, just thinking about those things and allowing yourself to practice self-care is so essential, especially now.

Krissy Dilger: [00:11:51] I think that is a really important part of all of this. Self-care is something that we don't always prioritize, but we definitely should. There are many different types of therapies and mental health professionals, for example, counselors, social workers, psychologists, psychiatrists, and more. What kinds of therapies work best for anxiety and depression and which type of medical professionals are able to best administer these therapies?

Katherine Chapman: [00:12:22] Yeah, so I think, there's, like, questions that you might want to ask when you're looking for a therapist. Like, do you have experience with working with people with chronic illness? Do you offer video visits? That's important right now for a lot of us. Do you do insurance? And a lot of times therapists will do a 10-minute conversation with you so you can kind of get an idea of what is their line of therapy. And we know cognitive behavioral therapy, definitely has helped people who have MS and lots of

other illnesses. It can help people conquer insomnia it's that, it's just a very popular, therapy that I use.

[00:13:05] And it's really recognizing how your thoughts and behaviors are impacting your mood and how they're so connected. But there's all kinds of therapies out there. So again, I would see if you could talk with the licensed professional counselors, licensed clinical social workers, like myself, psychologist, psychiatrist, and talk to your doctor and see if they have any recommendations.

[00:13:31] They might want to refer you to somebody who they know has experience with NMO, you know, or someone on the medical team might have that information then of course, you know, reach out to SRNA. There are so many support groups. They might have someone they could recommend. Yeah, just give it a chance, you know, there is no shame at all in getting help and seeing a therapist. I think it's, it's amazing when people want to, you know, practice that self-care. And I think that's one of the things therapists can help with too, is helping teach people those skills to relax and making sure that they are prioritizing themselves and, you know, doing whatever they can learn, for wellness.

Krissy Dilger: [00:14:13] Great. Thank you. So what medications work best for anxiety and a person who may experience panic attacks?

Katherine Chapman: [00:14:25] So this is a great question as well, and I'm not a medical doctor, so I can't comment on any particular medicines, but definitely talk with your neurologist or if you have a psychiatrist, you know, they certainly will be able to prescribe something and a lot of primary care physicians are very comfortable prescribing antidepressants and anti-anxiety meds. And just one thing to keep in mind, a lot of these medicines take four to six weeks before you see the full benefit. So just give it a chance. But if it's not working, then you go back to your physician and tell them, you know, this is not helping, and they'll figure out something else that you can try.

Krissy Dilger: [00:15:10] Okay, thank you. So how do we deal with mood changes with NMO? This person's son has mood changes and it's hard to deal with.

Katherine Chapman: [00:15:22] Yes. I think this is a, probably a challenge for a lot of family members. And friends and families can definitely make a difference. And I think I will let your loved one, know that or your son, that you are there to listen and help and practice flexing your athletic listening muscle, because that will really foster laugh and productive dialogue. Do your best, not to make assumptions. And, you know, some of the questions you might want to ask, you know, ask questions like "is there more that you want to say about that? Could you tell me more? How do you feel about that?" You know, there's no wrong or right feelings. Ask them, "how can I best support you right now?" And then some tips on just open and positive communication is to give people your full attention. You'll get rid of the screens, turn the TV off. Don't have your phone around. So that person knows that you are fully present there listening to them. So "I had a really hard day and I felt so exhausted, you know, can we hang out for a little bit and then do the dishes together", because when you are doing the "you" statements, like "you were so selfish", that generally makes people feel defensive where, and then being defensive basically shuts down any effective communication.

[00:17:12] That's another important thing is really try to not take things personal. And you know, again, we can't assume or think that we can read other people's minds. That's a very common thinking trap is that I'm thinking they can read our mind or they can, or we can read theirs. We definitely can't do that.

[00:17:29] Give everyone a turn to talk. So take turns with being the speaker and the listener. So, you may even want to validate the feeling, you know, that someone's discussing, like, "Oh, you know, that makes perfect sense to me that you would feel so frustrated about those symptoms". And, just try to come from a place

of love and non-judgment, you know, no blaming.

[00:17:55] And if you do find yourself getting really frustrated in conversations, please, again, practice breathing, exercise. You might want to put a hand on your heart, a hand on your stomach and just really pull in that diaphragmatic breath, into you and feel it coming in and out. And you might want to, even before you have a conversation, agree to take a time out.

[00:18:19] If things are getting too heated and, you know, meet at a later time. You know, practice self-soothing again, try not to take things personally. And you might want to write down what you want to say before, so that you have it there and can clarify what you want to talk about.

Krissy Dilger: [00:18:37] Great. Thank you. And then are there any community resources, you know of for people who don't have health insurance or the financial resources to pay for therapy?

Katherine Chapman: [00:18:51] Okay. Yes, there definitely is options out there. So in those States you can call 211 and ask them what places in my area have sliding scale counseling.

[00:19:06] Also, if you, you know, a good place, maybe even to start as if you are working to check into your employee assistance program at your job, because sometimes they will provide the counseling to free counseling to the work, the employee and their family. So that's a possibility. Check with schools and universities, like at UT Southwestern, we have the UT family study center where they don't even bill insurance, it's just the \$20 flat rate for, for families.

[00:19:37] So I would, you know, try those things. I, you know, I think there's definitely, help out there if you need it.

Krissy Dilger: [00:19:44] Those are some really good suggestions. Thank you. And then how can a person with anxiety and depression explain this to their family and friends? And for some people, the stigma of mental illness can keep them from reaching out for help. Do you have any advice for someone who may be feeling this way?

Katherine Chapman: [00:20:03] Yes. I mean, it, I think it's so important to have that open communication with your family and, again, letting your loved one, know you are there to listen and help. And you know, who is part of your support network? You know, even maybe writing out a list of things that people can do because a lot of people want to help, they're just not sure what to do. But if you can give them a list of these are things that we would love somebody to do and let people pick, you know, and don't, you know, assume that they don't want to do that. Just please give them the option of letting them decide if they can do that or not. And so I think yes, family and friends can definitely help.

[00:20:46] And back with like the mood changers, you know, it is very difficult for it to be around somebody who is depressed or anxious. So please, you know, people, have self-compassion for yourself and I'm very big on this and being very kind and gentle to yourself, you know, treating yourself like you would a great, you know, a really good friend and also just realizing, you know, that everybody has gone through some suffering in that we're all connected as humans.

[00:21:18] And when you're practicing self-compassion, you're being mindful. Instead of like ruminating over things or be mindful of your present moment, and just really taking it in and practicing that. So again, like with the mom, you know, with her son, I would, I can just say, please give yourself compassion. It's okay. You know, it's not going to be perfect. I'm doing the best I can. And just being really gentle with yourself. You

know, all the family, because I think it takes again, all the family is going to adapt in their own time. You know, we can't put any expectations on that, but people just need space and time to process, you know, what their new diagnosis and what this means to the family.

[00:22:02] And I just so encourage people to not cut out fun, recreational things. Please keep up with date nights. Please have family nights, have fun. Keep up with outside activities and encourage the individual and the family to keep up with those things. I just think that's so helpful, just so helpful how to keep up with those things. And again, just letting your family know that you're there to talk and practice that active listening skill, the skills that we were talking about.

Krissy Dilger: [00:22:36] Okay. Great. Thank you. I know you, you already touched on this a bit, but are there ways for family and friends to help someone who is experiencing depression and anxiety and if a family or family member or friend notices someone is having trouble, but that person hasn't reached out to them yet. Is there anything for that family member or friend to do? Or is it best to just wait and let somebody come to you?

Katherine Chapman: [00:23:10] Well, I think you could, you know, gently and in a respectful, loving way, tell them things that you might be noticing, you know, different symptoms or depression or anxiety.

[00:23:23] Because certainly if they are recognizing that in their loved ones, they, it can be treated. I want them to get help. And this is something that, it was from a movie that I saw about suicide and they use this ACE or you ask, so you just basically directly ask people, are you having suicidal thoughts?

[00:23:47] Engage with them, you know, let them know you're there to listen and that you care. So it's ask, you know, directly, engage and care. You know, and that engaging and caring part can be, you know, helping them to find a therapist to work with or get them to their doctor and be in on the visit and bring a list of questions. And, you know, I think most physicians are going to, know that, you know, all these emotions or depression and anxiety that these, you know, are common in the population. But just especially more so when you're dealing with NMO,

Krissy Dilger: [00:24:27] Okay. Thank you. I think that is the end of our questions we received. Is there anything else you wanted to add or touch on before we wrap this up?

Katherine Chapman: [00:24:39] Yes, we do. I guess just a couple of take-home points that just every person and family is unique, you know, they're all going to have their own challenges. And just that not everything is going to be about NMO. You've got other challenges, you know, in the world right now. So you can just remember, it's not always about NMO. Again, don't eliminate recreation. Please do the fun. Keep doing those fun things. Limit your news intake and social media because that can, that does stress out a lot of people that I work with. And just know that it takes a team and, you know, as a medical team, we want to be there for you and your family.

[00:25:22] Try to do something that's relaxing every day. Give yourself permission to do that. It's just not even an option now. It's essential to be eliciting that relaxation response every day, which could be through listening to music, repetitive sounds like listening to ocean waves, repetitive prayer, aerobic exercise. That's another one. And just, you know, noting your body, like where am I holding tension and tightness and work on your breathing to try to release some of that and then use your inner and outer resources.

[00:26:00] Please reach out for help. I'm just going to give the hot suicide hotline just in case. It's 800-273-TALK. (8255). 800-273-8255. And again, if you're a family member, just ask, engage with them, care about them and try to help them, you know, the best that you can learn. And self-compassion. Please check out

self-compassion dot org. There are guided meditations on there to help you build compassion for yourself and exercises you can do. And just recognizing, you know, that we're not perfect, but we're going to be okay.

Krissy Dilger: [00:26:40] Great. Thank you so much. And thank you for your time today. I think this resource will be very helpful to all of our members, and I think it's a really important topic that deserves this attention. So thank you.

Katherine Chapman: [00:26:56] Yeah, it definitely does. And thank you so much for having me. I really appreciate it.

Krissy Dilger: [00:27:01] Thank you.