

The Mind-Body Connection in Rare Neuroimmune Conditions

Exploring the Relationship Between Mental Health, Fatigue, and Cognition

You can view this presentation at: youtu.be/bfwhH_kez6Y

[00:00:05] **Dr. Lana Harder:** I'm Dr. Lana Harder. I'm delighted to be joined by our Post-doc Fellow, Dr. Natalie Escalante, who has spent the last year, I guess, working with all of us in our clinic in Dallas, which I'll tell you a little bit about. I also had the chance to attend the SRNA Family Camp this summer, and we're just glad to be here to talk to you today about the Mind-Body Connection in Rare Neuroimmune Conditions.

[00:00:33] There's so much to talk about on that subject, but we do want to zoom in on mental health, fatigue, and cognition this morning. I want to start by acknowledging the patients and families impacted by rare diseases, who have taught me what I know about working with this population over the last 15 years or so. Also want to thank SRNA for bringing us all together and for events like this, where I continue to learn and grow myself.

[00:01:06] I want to acknowledge the team here in Dallas that was started back in 2009, as was mentioned with Dr. Greenberg. We have grown, we used to be a half-day clinic once a month, and now we're in clinic just about every Friday for most of the day. It's great to come together with a team of specialists to serve the patients and families each Friday.

[00:01:34] So, if any of you are new to neuropsychology, I just wanted to mention what we are looking for, what we are doing as neuropsychologists focused on these conditions. We are known for being expert in these brain-behavior relationships, and focus a lot on cognitive functioning and thinking skills, with a lens toward how a brain-based or a central nervous system problem would impact those things and would impact life overall.

[00:01:46] So, how does a rare neuroimmune condition show up in daily life? That's what we really want to get at, so that we can identify the strengths and weaknesses for those who come to see us. As humans, we all have those -- things that we're better at, things that might be harder for us -- and then we want to develop a tailored plan to address any areas of challenge.

[00:02:31] In neuropsychological evaluation, we do a lot of standardized testing. So, sitting at a table, a paper-pencil question answer, some computerized measures, to find out if the person we're working with has any

difficulties in things like attention, memory, how quickly we process information. We look at mood as well, behavior, quality of life, and we'll talk some more about that.

[00:02:59] I always want to make this point. So, when we talk about neuropsychology, we are clinicians, and we're also researchers. As a clinician, we are looking at an individual in front of us, right? We're really tailoring everything we do. Our whole assessment is tailored to that person, and the plan that we come up with at the end of the assessment is tailored to that person.

[00:03:23] When we think about research, we're really studying more at the group level. We've heard a lot of great research reports today, we're going to intertwine a little bit of that in the talk this morning. And so, I just want to say that, as we describe problems we have seen at the group level, we also want to acknowledge that not everyone is impacted the same way, and not everyone experiences the things that we'll talk about.

[00:03:50] A final point on the role of neuropsychology: in our program, we provide consultation, so we come and check in with the patients and families. We also provide both brief and more comprehensive evaluations, like I was talking about earlier with standardized assessment. And then, we really focus in on transition planning. So, we are pediatric neuropsych folks, and we are looking at that transition to adulthood to make sure that our patients have what they need as they enter that important stage of life.

[00:04:28] Education and clinical training are really important. Dr. Escalante is a great example of a trainee who has focused in in this area. I think we all appreciate, with rare disorders, we really want to spread the word and spread that expertise. So, it's very exciting and gratifying to get to teach this next generation. We see the conditions we've been talking about this weekend, and I just have this slide here for that. I also want to highlight some common and overlapping areas that we work with.

[00:05:04] So, we've touched on this a little bit -- cognition being a major area. We're also considering a number of other things that could impact a person's thinking ability or their daily functioning. Fatigue has been a very hot topic, I've noticed, in some of the sessions, and we really want to dive into that a little bit. Also, mood. We know that for individuals with rare neuroimmune conditions, they are at risk for problems in cognition, fatigue, quality of life, and also mood.

[00:05:38] So, there is that risk, which is why we, from the start of our clinic, really wanted to be proactive and make sure we were connecting with all of the patient families that come through the clinic, so that we could pick up on these things and address them as quickly as possible. I think it's important to note a person's life stage is very critical when we're doing an evaluation because that can direct what the expectations might be in the world around them, and we want to make sure we're keeping that in perspective.

[00:06:13] So, one thing I think is really important to address -- we could do this with a variety of our common symptoms -- but a question that has come up very frequently over the years that I've been doing this is: how can you tell the difference? Is someone experiencing fatigue? Are they experiencing depression? Maybe it's both, right? So, looking at where that overlap is, I think, is really critical, and then looking at how we can start to separate those two things.

[00:06:44] So, I was recently reviewing our clinical criteria for depression, and in it, loss of energy is one of the symptoms on the list. There's diminished engagement that you can see in depression and fatigue, changes in sleep, and so forth. So, when we start to think about how are these things different, we're really looking more into: is there this persistent depressed mood, sadness, emptiness, hopelessness, thoughts of death and dying, among other symptoms?

[00:07:20] And then, if we can rule out those symptoms and start to look at, okay, it's the feelings of exhaustion that are leading to this reduced engagement, that really helps us separate those. And, as I mentioned before, it can be both of these things. So, it isn't always going to be one or the other. One thing that we've studied for a while is the association in these symptoms.

[00:07:49] So, we often see this track together, where problems with cognition then correlate with problems with fatigue and problems with mood. I had a dissertation student, Dr. Cole Hague, who's now at Children's National, who did a great study and saw that, in a model he created, depressive symptoms were predictive of cognitive impairment. And so, these things often, again, track and overlap. Something we see broadly in the literature is when we address one area, we're often also addressing other areas.

[00:08:24] So, that's a really good thing. I think a critical takeaway from today's talk, and it's all about prioritizing. So, if we know that there are symptoms, there are difficulties -- let's say, you've had a neuropsychological evaluation and you get this list of recommendations -- that can feel really overwhelming. Where do we start? What should we do?

[00:08:50] And I think a couple of questions that would help drive those decisions and those priorities are: What is the most distressing? What's interfering the most with daily life? And then, pick one or two to begin with and go from there. Again, with the thought that when we address one or maybe two problems, we then get some benefit in the other areas. With that, I will turn this over to Dr. Escalante.

[00:09:22] **Dr. Natalie Escalante:** I'm just going to go back one slide really quickly. So, these last two questions, I want everyone to just think in their mind what is something that might be most distressing, or what's one thing that interferes with your daily living? And keep that in mind as we talk about these next few areas. So, I think it's really important to highlight that mental health is health.

[00:09:49] It is as important as attending your medical appointments, it's as important as sleep, and eating, and drinking water. Our brain is a part of our body, and the two are very, very connected. As Dr. Harder was explaining, when we address one area, we might be addressing another area, and so, making mental health a priority, is very, very important.

[00:10:16] And I think it can be overwhelming on knowing where to start or how to continually do it, but I think taking smaller steps and making sure that if you can find one thing to focus on every day, then you are going to make exponential growth. So, what is mental health? So, I can't really see these slides here, but --

[00:10:43] **Dr. Lana Harder:** Do you want to switch places? Let's do that.

[00:10:44] **Dr. Natalie Escalante:** Thank you.

[00:10:46] **Dr. Lana Harder:** Sure.

[00:10:47] **Dr. Natalie Escalante:** Sorry. So, mental health is a general sense of well-being. It can be how we manage stress, how we relate to others, and how we make choices. It's related to how we think, how we act, how we feel, and it is important across the lifespan, so when we think about mental health, from elementary age all the way up into our older years.

[00:11:13] And our mental health is linked to our physical health as well. That's been demonstrated in the literature, and so it is something that we need to take care of, like we take care of ourselves every single day.

[00:11:29] I think this is such a great graphic because I think there is this expectation that life is supposed to go in a general straight direction. But, as everyone in this room knows, there are so many instances and so many events in our lives that can change that trajectory. I think it's important, and we were talking about this, and I like this graphic because it's not always just up or down -- it can move side to side.

[00:11:57] Life can really take you on different paths and different journeys, and it's really about how we are present in that moment, and how we are present in the things that we can control, and the things that we can manage in the day to day, and so that is always nice.

[00:12:19] All feelings are valid. So, I think, especially with our littles, feelings can be very difficult to manage, and we have all types of feelings. We have feelings from just more basic, like I feel angry, or sad, or happy. And then, as we get older, we realize that feelings can be more complex. So, fear is actually maybe worry or anger, and sadness could be grief. As we think about these feelings and their impact, it is important that we feel the spectrum, that we take in all of the feelings, the good, the bad, the ugly, and we experience them in our bodies, and we acknowledge them, and we are intentional about how we either describe them, or discuss them, or embrace them.

[00:13:14] I think about feelings as having to go through them; there really is no way to go around them. When we have too many strong feelings, if they start to build up, they can come out in ways that aren't pleasant or aren't fun to manage. I think this is a great representation of the different types of feelings that can fit into the main ones that we think about. And so, sometimes it might be helpful to ask yourself, when you are experiencing a big emotion, "What is this?"

[00:13:49] Feeling wheels like this can be really helpful. There are a lot more online that really go in-depth, but I think this is a good place. So, if you feel yourself feeling sad, you can maybe take a step further and get introspective and think, "Okay. Am I feeling lonely? Am I bored? Is it grief? What's going on there?" And really having those conversations with yourself or with a trusted friend or family member or a trusted professional, I think, is a great place to start.

[00:14:21] And then, we talk about spilling over the edge. So, all of us have our baseline -- where we're at in our day-to-day and how we are feeling -- and then life events happen. You spill your coffee in the morning, or something doesn't go right, or you say the wrong thing, and it can feel like those things just build, build, build, and then it comes to the point where we just spill over. And I think everyone experiences those moments.

[00:14:51] And it's just about how we take a step back and how we can reflect on either finding ways to prevent spilling over or accepting that we spilled over. How can we get back to our baseline, and how can we get back to feeling much better? We're going to talk about those. I always like to talk about reset, refocus, restart, and how we use our resources. So, I think we can take every moment of our present being to take a second to reset, refocus, and restart.

[00:15:32] I think there's always assumption of, "Oh, well, I messed up today, I'll have to start tomorrow," or "I have to start on Monday or I have to start in the new year," whatever the arbitrary starting point is. But I think we can take every present moment, every hour, every second -- whatever it is -- because we're in charge to reset our intentions, to refocus, and identify goals that we want to achieve, and then restart.

[00:16:01] I think that is very valuable: to take ownership of that and to use our resources in order to identify, "How can I do that?" And, again, those are going to be some of the things that we are going to talk about.

[00:16:18] I like to think about our brain and mental health as a muscle. If you don't use it, it can be really hard to feel like, "I'm making progress." And so, the little things really add up, and I think that concept can be frustrating because we don't see the results overnight. If you sleep well one night and then you don't sleep well for a few nights, then you're not going to really get the benefit of what good sleep hygiene can do.

[00:16:50] And so, I think it's really important to make sure that we're finding little ways to continue to build on the steps that we're taking towards strengthening our mental health. And so, here are some ideas. I understand that it's not a one-size-fits-all. You may have tried some of these things, and they didn't work for you. That's okay. It just means that we have to get a little bit more creative or try something else.

[00:17:22] But when you find something that works for you, even if it's something as small as spending two to three minutes outside getting some sunshine, or listening to your favorite song, or calling a friend or a family member that just lights up your life. All of those are ways to improve our well-being and to strengthen that mental health muscle. So, some examples are journaling, just writing three nice things about yourself. If you don't have three, write one and try for two tomorrow.

[00:17:59] Going outside, hanging out with a pet -- I think my dogs are my world. They make me feel so happy, so if I can just cuddle with them for a few moments when I'm not feeling great, that's great. And so, I don't think that mental health and working on it has to be this big, grand plan, but it can be these little moments that add up together and that make worlds of difference.

[00:18:29] So, again, wellness can look like all different types of things. It can look like aroma therapies, smelling things that smell good. It can be seeking out professional help, whether that is psychotherapy or, again, working with a close friend or relative. And I think one of the biggest things is that we are stronger together.

[00:18:55] Here, we have a great community of individuals who have an understanding of how these neuroimmune disorders can impact us. And so, I think using your network and using the people who you've found can really be life-changing because you are really stronger together. We are all stronger together.

[00:19:27] So, I think my takeaway is to make time for mental health every single day, whether it's a few moments or 30 minutes, however much. So, we're going to do a little activity, and you might be looking at this like, "What does pizza have to do with mental health?" This is something that we do with our kiddos, but I think it is important, and it can be useful for anyone who is feeling overwhelmed or feeling like they might get close to spilling over the edge.

[00:20:06] So, I just want everyone -- it's called pizza breathing. And so, what you're going to do, and I'll walk you through: you can close your eyes, you can keep them open, whatever you want to do, but you'll watch the video. So, you're going to smell the pizza. You're going to smell and take a deep breath in through your nose, and then you're going to blow and cool down the pizza. It'll make sense when I play the video. So, we have pizza breathing.

[00:20:43] There's your pizza. Okay, get ready to smell. And take a deep breath in of that pizza. It's your favorite toppings and then cool it off. And breathe in through your nose, smelling that pizza, and cooling it down. Breathing it in through your nose and cooling it down.

[00:21:32] So, we know that deep breathing has a physiological response to our bodies and it can really help calm our heart rate, it can calm our breathing, it can calm our mind. And so, if there's ever a time where you

feel like you're spilling over the edge or you just need a moment, I want everyone to think about their pizza breathing. And so, a good strategy to help in any daily moments.

[00:22:02] Here are some resources if you are interested in finding a neuropsychologist, a psychologist, or a therapist. I'll let people take pictures. Oh, no. We all go back. And our next slide is just saying thank you.

[00:22:36] **Audience Member 1:** I'm biased, but as a psychologist, I think that was just fabulous presentation. I have a couple of comments. One is, the National MS Society has a Find a Provider site. So, you can go in, and they have identified psychologists with expertise in MS and neuroimmune conditions, and you can put in your geographic area and the kind of provider you're looking for, and they will come up with the names of people they have vetted. That's one.

[00:23:10] Second thing, here's a real quick tip I learned about how to determine if you're tired or depressed. So, let's say somebody offered you tickets to a Dallas Cowboys football game. I assume that's a good thing here, but anyway, if you're tired, you say, "God, I wish I could do that, but I'm so exhausted. I cannot picture myself getting there, sitting through a game, and getting home again and surviving." When you're depressed, you say, "I really don't care who wins that game." So, it's a real quick way to check in with yourself and maybe identify what's going on.

[00:24:01] My third is a question for you because Dr. Greenberg said I should ask you today instead of tomorrow. So, we've heard a lot at this meeting about different strategies for managing neuropathic pain, medication, and then stimulation, we just heard about. I know this isn't in your area here, but could you just comment because I think it's really important about mindfulness-based interventions being helpful with chronic pain, and I'd like people to hear that from you.

[00:24:34] **Dr. Lana Harder:** We may have some thoughts too. That's a great question and one that comes up. We ask every patient that comes to see us about pain for a good reason. We know that can really impact cognition, everything, mood. So, some of the things that I'm aware of: certainly, we have them talk to the medical professionals that are right next to us in clinic to see how we can manage medically. And I know biofeedback is one method that there's been some success with.

[00:25:12] We also want to be strategic about that tailored plan that I mentioned before -- just the daily schedule, looking out for things that might make things better or worse based on the person's day. I don't know if you have anything to add, but this definitely has come up, I know, in some of the kids that we've seen.

[00:25:33] **Dr. Natalie Escalante:** Yeah. I think scheduling is really important in finding when you feel less pain or less fatigue and really prioritizing, or being intentional about what you do in those moments when you are feeling less pain, so that you can feel like you were able to achieve or accomplish something and the most important things of that day.

[00:26:01] I think we've had patients who benefit from listening to their bodies. And when they are feeling tired, instead of pushing through, they're able to recognize, like, "I just need that break." And it's okay to need that break, or it's okay to take a warm bath, or to have a seat and do some pizza breathing.

[00:26:21] So, I think really honoring yourself, and you know your body better than anyone else does, better than your providers. And so, I'm really trusting that and listening to the cues that are there for a reason. And so, I definitely think that is one way.

[00:26:46] **Audience Member 2:** Yeah. Go ahead.

[00:26:48] **Audience Member 3:** Thank you for this. My name is Chris, and I have a quick question about patients that complain of severe fatigue after working sometimes throughout the day and having children and etcetera. What is your take on the use of Nuvigil or Provigil to help them be successful and continue to live their lifestyle the way that they should be able to, but the fatigue gets in the way so much, what is your take on Provigil and Nuvigil?

[00:27:21] **Dr. Lana Harder:** Yeah, so I'll say we don't have as much experience with that in the pediatric world. That would be a time where I would enlist the expertise of our neurologists who actually could probably speak better to that. Heard of stimulant use as well. With our kids, I haven't seen use of that drug as often. I don't know.

[00:27:44] **Dr. Carlos A. Pardo:** There is going to be a lecture on fatigue this afternoon, so I think that we can address those comments. But thank you so much.