

A Conversation

How Do I Identify a Relapse?

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[00:00:04] **Rebecca Salky, RN:** Hi, everyone. I am Becca. If you were here earlier or saw online, you already heard some of my story. But I have had MOG since I was four years old, undiagnosed until I was 22. So, I had lots and lots of relapses. I had probably more pseudo relapses which Dr. Wang will get into, but a lot has been learned.

[00:00:30] There's a lot of new information out there now versus 26 years ago. So, it's exciting to see all the improvements and growth that have happened. And now, Dr. Wang will introduce herself.

[00:00:44] **Dr. Cynthia Wang:** I'm Cynthia Wang. It's so nice to be here. These meetings are always so wonderful and learn something new from your stories, from the researchers. So, thank you, SRNA, for putting it on and inviting me to be part of this conversation. I have some slides. I don't want to go too far into it, but I think it might help lay, maybe, a groundwork or a framework to think about relapse because, I think it's exceedingly hard.

[00:01:08] And I think that's what many other meetings, when people talk about relapse, is that it's very hard to parse out. Is this an old symptom just flaring up and acting out? Is it something new? When should I be concerned? When should I call my doctor? When should I get testing done? So, I've used this analogy of fire because I think we often use this phrase, "put the fire out." That's what we try to do with things like IV steroids, plasma exchange, like Dr. Weinshenker mentioned, sometimes IVIG. So, I hope it is somewhat a helpful analogy.

[00:01:43] And then, in talking about definitions, I can't see it very well what I'm showing you, but I think many of you have heard all these things. And is it helping anybody? Is it just making things confusing? Is it leveling up your Scrabble game, maybe? But, yeah, I think one way to think about it is, how does an attack happen, or how does it progress?

[00:02:10] In some ways, you can think of it as, if we do have this comparison of it as a fire, it might start off very small and just burning slowly. And then, if we don't react and do something about it, it might grow to be really big. And then, there's going to be, at some point, regardless of what we throw at the symptoms and the exacerbation, it's going to fizzle out, and there's really going to be just damage, and nothing we can do at that point.

[00:02:40] Well, there is something we can do: we can start to do other things to help with building reserve and rehabilitation. So, I think what I want to illustrate with this is that, at different time points, there may be different treatments that could be appropriate, and different treatments may actually be harmful. So, if we're in the phase where we don't have a fire going, then dousing that whole area with water is not going to be helpful and could be harmful.

[00:03:08] Ideally, we would recognize symptoms at this phase, and early in the exacerbation, and we would treat before it gets too vast and it's harder to get as much recovery. But, realistically, maybe not until this point. And then, we may not even get to the hospital and get steroids, IVIG, plasma exchange until then.

[00:03:32] Taking this analogy a little bit further, I wanted you to imagine: what is your dream house? And I want this to be your experience, living in your house, your body, what the symptoms feel like. Some people might imagine something that's very large and opulent. Some people might have a house they want to be very simple and easy to take care of. Some people might decide to locate their house somewhere like an urban setting, and some people might want to live in as far away from people as possible.

[00:04:03] So, I think what I'm trying to illustrate is that, your body is different from everybody else's body, and only you know your experience. And I think that's sometimes what's lost. Your symptoms are very real. Oh, I forgot one last house. Because you're in Texas, I had to put this in. Does anybody know where this is from? Okay. Yeah. I think it was even before my time, but I have to put a Dallas reference in there. So, that could be your dream house.

[00:04:32] So, now imagine the unimaginable happens, without any fault of your own. Like, this sudden event: your house has caught on fire. And if you're lucky enough to be at a place where the neurologists and the doctors are well-versed in these, you might have all these treatments that are given in the early stages to help fend off the flames and try to decrease as much damage as possible.

[00:04:59] And then, with the help of your therapist, a social support network, you may eventually get to a point where the house isn't perfect, but it's liveable. You have some good days, and you have some bad days. It might depend on what the weather is like that day or what the season is. But you get a new sense of a new normal, if you will. So, with that process, you might get to this point where, again, it's liveable, but it's not perfect.

[00:05:19] And that's what I think might be a helpful way to think about this. Is it just something where your body isn't working? Maybe things like heat, fever, infection are just going to destabilize your experience of living in that place? Or is it, like, a brand-new fire? In which case, we do want to identify that and categorize it accurately because it does represent disease breakthrough. And the earlier we treat that, the more we can maybe reverse damage and facilitate recovery.

[00:05:59] And then, it's really important in discussing or thinking about, for a person who's only had one attack and somebody told you this was idiopathic, well, it's not idiopathic anymore; it's relapsing. So, should you be on an immunosuppressive treatment? Alternatively, if you have neuromyelitis optica or relapsing MOG, then you might want to be on a different treatment because, obviously, that did not work. These are the factors to think about: Where is it located? If it's in your legs and you've only had eye involvement, then that's pretty concerning.

[00:06:31] And I think that's why I don't want to say, "You have to wait 24 hours," because if it's a brand-new symptom and it's severe, then the sooner you let your physician or a medical care team know, the sooner they can act on that information. Is it a symptom that you had weakness, but it was never to the point you

couldn't walk and now you can't walk? So that's unusual. That doesn't seem to be something a pseudo-exacerbation could cause. And then, lastly, are there alternative causes that could explain that? And I think many of you are familiar with this: these are the things that we think about with a story, an exam that makes sense for new inflammation.

[00:07:12] We don't even need to get to testing, but sometimes it is confusing, or there are pieces that we can't quite parse out without getting some testing. Sometimes that's an MRI. Actually, we do something in our clinic called optical coherence tomography, where we look at the retina layer thickness. And sometimes, even before somebody has symptoms, we can see that there's swelling, and that has sometimes led us to act even faster than the symptoms have presented themselves.

[00:07:38] Okay. I think I would just briefly cover a few more things. Again, new inflammation; definitely, you want to change therapy. Again, here's your symptom severity. This is your experience, and this is on the other axis. That is what we doctors are looking for: evidence of inflammation. So, it makes sense that we would want to find this. And then, in the case where the optical coherence tomography identified new inflammation, we still probably should change therapy, and it's lucky and good that we didn't wait to see what could have happened.

[00:08:17] But at the same time, if we don't find any new inflammation, but you're living with severe symptoms, that's still not good. And that's, I think, an opportunity to talk to your doctor to troubleshoot why that is. And then I think, at some point, we want to move you into this frame where you have a sense of what it's like, that there's some ups and downs, and there are things that you can do to get over these exacerbations faster. And, hopefully, this was where the Q&A and discussion will go to -- just what you can do.

[00:08:52] And I think I'm really interested to hear from Becca, because I think she's talked about thinking about how to track your symptoms closely. How does it change with other things, like sleep, exercise, psychological stress, things like that, because I think only you know what it's like. As a physician, I'm looking from the outside, and I can help. And I've seen cases where this, and this often is, exacerbation or pseudo-exacerbation, but I think your lived experience is more important than anything I can do to test.

[00:09:24] And then, I guess one other thing, it's just unlucky you had this fire of your house, but, unfortunately, it's not a pass that you can't have something else, like, a flood or something. So, looking for other potential conditions is also super important. And, hopefully, you have a clear channel of communication with your health care team. I think that's very important. And if you do not feel like you're being heard, then I think that is an opportunity to look and seek an opinion elsewhere.

[00:09:59] **Rebecca Salky, RN:** Great. Thank you so much. Well, I'm going to make a comment and then ask a question, and then we'll maybe do one question from the audience before lunch. So, comment is that: I think, as a patient, it gets really hard because you have new symptoms all the time, and you're like, "Should I be calling my doctor every day?" That can feel like you're really a burden, which also, the stress of that, can make your symptoms worse.

[00:10:32] So, I think it just becomes challenging, as patients, to know: What is even having this for 26 years? What is a relapse? What is a pseudo-relapse? How are my symptoms changing? Am I having progression despite not having true relapses? Those are some questions. And I guess that leads into my other question, which I asked Dr. Wang to look into, before I knew there wouldn't be a lot out there about this. But the question I had was: What is really happening during a pseudo-relapse? Is there inflammation that's causing damage to progress over time?

[00:11:11] Do we know for sure that these pseudo-relapses are just a flare-up of symptoms, but no actual damage happening? I think that would be a really interesting, important topic for you clinicians in the room to look into. Wink, wink. All right. Those are I guess -- that wasn't really a question -- those are two comments.

[00:11:33] **Dr. Cynthia Wang:** Yeah. I think in the tests, I had italicized biomarkers because I think we have great biomarkers now for diagnosing the disease. We don't have good blood biomarkers for predicting or capturing evidence of a relapse. And then, I'm a pediatric neurologist. I think you had symptoms in your pediatric during your childhood. And I think there's other things to think about with the tests that might require sedation for MRI.

[00:12:00] So, I think less-invasive or non-invasive biomarkers are very important. I don't think there is much data, and there is an umbrella of conditions that we're discussing here. In NMO, I think serum GFAP has been looked at. In multiple sclerosis, things like serum neurofilament light chain. Imaging is getting to be better, where you have higher Tesla magnets, and sometimes that can look and identify cortical atrophy or subtle brain atrophy without having clear attacks.

[00:12:34] So, I think we're getting there; the conversation is getting there. But, yeah, I think even if it's not inflammation that's causing injury, it's not good to have symptoms all the time. It's like an opportunity cost -- you can't go, and you don't have the energy to do exercise. Pain may be limiting you from spending time with loved ones. And so, I think there's an element of that and the mental health burden that comes from having all these symptoms.

[00:13:07] **Rebecca Salky, RN:** Definitely. Thank you. Do we have any questions from anyone in the room or online maybe? No. Any questions back there?

[00:13:22] **Audience Member 1:** Over here.

[00:13:23] **Rebecca Salky, RN:** Oops! Sorry. Vision impaired. Thank you.

[00:13:27] **Audience Member 2:** Oh, okay. So, I was diagnosed with transverse myelitis one-and-a-half years ago, but I also have a breast cancer that has been in treatment now with hormone therapy. I am getting new symptoms. I went with my doctor and she said, "That is a reactivation of symptoms. We don't know why. Probably you have a virus." But not only that, my thermostat is lost; I am sweating, I am freezing. They say, "It's the hormone therapy."

[00:14:04] Then the oncologist says, "No way I'm taking you off the hormone therapy. They need to find something else." Now I am going with a specialist in perimenopause. And since this is very, very specific, the appointment is for May. Meanwhile, I am having a lot of medicine just to not treat my disease but my symptoms. And I am always thinking, I am moving away from this diagnosis? Is just the breast cancer that is bothering me? What is now? Because it's like every day, I have something else to say: I have this, I have that.

[00:14:48] When I have to write to my doctor, I am feeling I cannot keep asking her. So, I always wait, like, two months: "Okay, I am having this," and then I got the back, "Why you didn't tell me before?" I am losing my equilibrium. I cannot work. I have a stand workstation. I cannot work standing up because my legs are just quitting. But I understand with TM. So, how can I make all the doctors that I have around to talk between each other and say, "This is from this," "This is from that," "We have no treatment for this," or "How can we help her?"

[00:15:34] If you see me, I have nothing. I jump, I run, and then I get tired and just rest, and that's my life. One day, is the fatigue, and see I have never had fatigue as I am having since June. Sometimes, it's twice a week.

I say, "I am losing my life in this way." I am pushing, and pushing, and pushing, but it's like, "How can I help myself other than being mindful, doing my yoga, my relaxation, and all the things that everybody say to me?"

[00:16:10] But just think that I am still doing well and nothing is wrong with my cancer. That was the first thinking: "Oh, you have metastasis." Okay, this metastasis, I know how to deal with that. But, "Oh, it's a new tumor." Oh, okay, let's go with a new tumor. But then: "No, you had MS." "No, you had TM." Okay. I'm glad I had TM. That's good. So, I am in that point, I don't know who to talk with. I don't want to be a burden for my doctors because all of them are beautiful. All of them are listening me all the time. And I think here is more people that have not only one disease but more around. So, thank you.

[00:16:58] **Dr. Cynthia Wang:** Thank you for that. I thank you so much for sharing your story, and I think that just indicates how complicated things are, and how, as doctors, we don't have all the answers, or that it may not just be one factor, it could be several factors. And how do we act on what we can control or get information on what we can control? And I think sometimes that leads me to talk a lot about things that seem common sense, but maybe not all of us implement that well, in terms of getting enough sleep, trying to eat well. I heard you do relaxation, yoga. I think those things are incredibly important.

[00:17:35] And then, I think in telling your story and finding people like you who have had similar experiences, I think Becca can talk to this in terms of support groups and having a community of people. I think, more than anything else, just feeling validated that what you're going through is really tough, and other people have been through similar times -- and sometimes they've gotten better -- and that can be really helpful. I think just having that community can really be helpful for getting through this time where things are not quite clear.

[00:18:09] **Rebecca Salky, RN:** Yeah, I agree. Community is very important. I also do hope that in the next 5, 10, 15 years, as we see improvements in care, we start seeing more coordination of care outside of just neurology, immunology, ophthalmology. I think we need all different specialists involved. A lot of people tend to have more than one condition, and it can be really confusing to know what's what. I'm in a program right now where I would love to work to change this in our system. I think it's one of the biggest issues right now. We do one more question. Yeah. Okay.

[00:18:58] **Audience Member 3:** Hi. Thank you. Just wondering, if someone thinks that they're having a relapse and they decide to go to the ED -- let's say they're traveling or they don't have ready access to their typical physicians -- are there any good strategies or tips when interacting with those physicians on trying to avoid the rigmarole as much as possible? Would it be like: "I need imaging to get a better picture of what's going on," or "I have specific biomarkers that I need to check," instead of having to wait maybe hours and days until you can get in touch with the right people to then get those tests done? Do you have any tips for that?

[00:19:54] **Dr. Cynthia Wang:** Yeah. I think for patients who may not have the access to more of an academic or larger center, where you're going to be educating the physicians more than they can teach you anything or tell you anything about your condition, sometimes having something in written form that perhaps your neurologist or your immunologist could draft for you:

[00:20:20] "This is the condition. I'm this important person at this academic institution. This is my email or my office phone number, and you can page the person on call," or something like that. That might just be the best way because then they get what they want. They get a direct answer from an expert that they speak the same language with, and they can implement those tests or treatments as soon as possible.

[00:20:44] **Rebecca Salky, RN:** I think that's a great point, and that's what I had for most of my childhood, and now I live near an academic center. But before, I would have a letter from my doctor saying, "She has

neuromyelitis optica-like syndrome. This is what we're treating her with." And then, now, I can only really speak to MOG, but the MOG Project has a fact sheet to hand to new doctors that might not know about it. So, I don't know. I would ask SRNA, but perhaps they have resources for the other conditions too.

[00:21:18] **Dr. Carlos Pardo:** The other thing is -- exactly, just go to information that is available. But a very low-hanging fruit for everybody in this room with neuroimmunological disorders is, any time that you are experiencing an exacerbation, the first thing that you need to make sure is that you don't have an infection. Infections are the most frequent cause of pseudo-flares and exacerbation of symptoms.

[00:21:45] That doesn't mean that NMO is coming back. That doesn't mean that MOG is coming back. That means that, basically, your body is under a lot of stress due to an infection. Urinary tract infections are extremely common, so you need to rule that out quickly, and you need to tell the ER person who is seeing you, "I need to check my urine because it maybe a urinary tract infection." If there is any problem like pneumonia or any cough or upper respiratory infection, you need to pay attention to that.