

Symptom management panel

You can view this presentation at: youtu.be/ox1Bju38d-o

[00:00:00] **Dr. Grace Gombolay:** I get asked this a lot, we talked a lot today about different treatments, different management, things that we can do to help. I get often asked what else can I do? Like I'm doing the treatments, I'm coming to my appointments, I'm getting my imaging studies, what else can I do?

[00:00:20] And so I group all of this into lifestyle changes that can be helped. And then this is not, this is true for everybody. Not just if you have a neuro immune disorder or other chronic illness or any disease. I think this is important just for health in general and you'll find a theme for all of this.

[00:00:35] Number one is sleep. I think sleep is underrated. No, nobody gets good sleep. We're all on our smart phones. I'm also guilty of this, right? Right before bed you're like, okay, I'm gonna look at this, I'm gonna do this. I'm gonna scroll on Reddit or whatever social media platform that is your interest.

[00:00:51] I'm gonna watch a video or something like that. For some people it's soothing, right? This is you've now associated that with sleep. But the thing is that what we know and you guys are all aware of this, is that light, including if you have the blue light filter on your phones, it does tell your brain to wake up.

[00:01:04] That's how our brains have been wired. If you have light that comes in through your eyes, it tells your brain it's time to wake up. So, if you have trouble falling asleep because you have been watching TV or on your screen or what have you, that's gonna affect sleep. Not only does it affect you how well you would fall asleep, but also quality of sleep.

[00:01:20] So how well do you sleep at night? So, there are certain apps and things out there to help you with sleep. It's particular type of cognitive behavioral therapy or CBT for insomnia. A lot of those apps will tell you, turn everything off, don't do this. Don't look at screens. At least an hour before bed.

[00:01:38] Because it tells your brain time to take a break and time to rest. The next thing is diet. And I think everything is in moderation. So, I tell my patients and families more fruits and vegetables if you can. There's been studies looking at high fiber can help prevent relapses or reduce inflammation.

[00:01:58] The thing is that processed foods, excess sugary foods also probably plays a role in inflammation. I think everything in moderation. Am I saying that you can never have that piece of cake or never have that treat or that delicious lemon square we have for lunch? Absolutely not. Just you know everything in moderation.

[00:02:16] And just think about what you're eating and just try to incorporate more fruits and vegetables in your diet. We talked briefly about the gut and its link to inflammation. There's a lot of studies now looking at the gut microbiome, meaning the bacteria that live in your gut. And so, there's things like yogurt that has healthy microbes and things that can help with all of this.

[00:02:38] And same thing with the fruits and vegetables seem to alter that and alter immune system. 50% of your immune cells actually interact with your gut. And so, there's a lot of interest in research in the types of microbes or bacteria that are living in your gut and how they'd affect inflammation.

[00:02:54] Next is physical activity. We touched upon this earlier. We think that but if you're having all these symptoms, it's hard to do physical activity and that is true. But try to get in and whatever physical activity that you are able to get in and that will help your symptoms, even if it's just standing up or even just if you're bed-bound or wheelchair-bound, even if it's just lifting your arms up or doing whatever movement you can.

[00:03:19] Even if it's minute, small, it'll help and go a long way. Vitamin D There's some earlier studies that talked about vitamin D, how it affects the immune system and how low vitamin D seems to be associated with increased risk for relapses. For example, in multiple sclerosis, there's some people who don't believe in that, but I think vitamin D is relatively harmless to take.

[00:03:42] Unless you take the whole bottle, please don't take the whole bottle because then you'll get kidney stones and all sorts of things. But if you take what's the recommended amount and often, a lot of our patients are low on vitamin D, and if it can prevent relapses, why not? And if you take too much of it, you just pee it out.

[00:03:57] Mindfulness activity. So, taking a break, and I'm gonna talk about this in a second too. Is there mindfulness that you can do, take a break, do five minutes of breathing? Some people do yoga, some people do -If you're religious or spiritual, things like prayer or meditation, things like that can really help with a lot of these symptoms and social activities.

[00:04:19] It's one of those things when you're feeling crummy if you need to take a break, totally fine, but for a lot of people with a lot of these symptoms and stuff that they're experiencing, it's easy to be isolated, to stay in your house, to stay home, to not go out and do things. But if you can go out and just do, even if it's go out and meet with somebody for 10 minutes or call somebody on the phone, some social interaction.

[00:04:42] We as human beings are generally wired to be socially interactive with others, to have community with others. And so really try to interact in social activities. And then hobbies, what are things that give you meaning in life? Because if you think about, and we've talked about this earlier, what are your goals in life?

[00:04:58] What gives you meaning? What drives you every day? What makes you happy and fulfilled? Think about those things and go ahead and try to partake in those activities because that's gonna help you. And finally, I mentioned this, but I'm gonna highlight this again.

[00:05:14] Limit screen time and social media. And I get on my soapbox for a second here. Social media in a way does keep us connected, right? When I'm on social media, I'm in old school Facebook, which nobody uses Facebook anymore, but I'm still on Facebook and a lot of my high school friends and college friends from 15, 20 years back are still on Facebook.

[00:05:33] So I can keep up with them. But at the end of the day, a lot of, there's a lot of studies on this, social media actually makes people more anxious and more depressed. Because what we do is we put our best faces on social media. Once in a while you'll find somebody who will share their story, their real story, their real struggles.

[00:05:49] But most people are gonna be like, oh, look at me. I went out to dinner at this fancy restaurant today. Or look at my kid that accomplished this today. And I'm glad for those things, and I'm glad that we're celebrating those things. But what you'll find is a lot of people become really depressed.

[00:06:02] They become jealous. And it turns out to be like keeping up with the Joneses, right? You're like, oh, so and so had this, and now I don't have this in my life. And then it started becoming depressed. And so social media in a way does keep us interconnected in some ways, but at the same time does not in a different way.

[00:06:18] It doesn't keep us connected, like the social activities. I think of social media when you're scrolling through like Facebook or Reddit or Instagram or TikTok or whatever you're getting all this content, but are you really interacting with other people meaningfully at a different level? Sometimes you are, sometimes you're not.

[00:06:34] So food for thought, again, limit it. I'm not saying don't do it at all but limit that time on social media. Let's talk about fatigue. Fatigue is probably the number one symptom that a lot of my patients come in. Even in seeing children who have lots of energy, fatigue is probably one of the most common symptoms they come in complaining about.

[00:06:55] And unfortunately, it's very challenging to treat, as all of you guys know all of this. I'm gonna go over all of these things again, all of this, but at the end of the day, it's still hard to treat, right? So again, good sleep, diet, exercise, things about vitamin D. There are some people who have said, "Oh, when I take vitamin D, I feel like I have more energy."

[00:07:16] If that is true, more power to you. Again, just don't overdose on vitamin D, but go ahead and take it if you think it helps you. This was touched upon earlier by the therapist in the rehabilitation panel, taking breaks. Think about what your goals are for the day. Think about what absolutely needs to be accomplished.

[00:07:34] All of us are very driven people and so I think, and I do this all the time, I make a list of 25 things. I'm like, this has to be accomplished today. And if I don't accomplish 25 things, I feel really depressed because I'm like, I didn't get anything done. And I'm like, am I lazy? Am I incompetent?

[00:07:48] No, just no one can do 25 things in one day, right? And so, think about prioritizing. These are the absolute important things that have to get done today. These are things I would like to get done and if I get it done, Great. But what do I actually have to get done? And then start planning, okay, I can do X, Y, and Z, but I need to take a break in between.

[00:08:06] because I know this thing's gonna take me a lot of time or energy. And if you can, naps can be helpful. Naps are with a caveat going back to sleep. So, if you go to a sleep specialist, they're gonna be like, don't take naps. It's gonna affect your nighttime sleep. That is totally true. So, try, if you're gonna take a nap, don't take it later on in the afternoon, evening, because that will make it harder to fall asleep.

[00:08:25] But for a lot of people, they need a nap, even if it's 10 minutes, 15 minutes to get that energy back. And so, plan the activity. So, I like this to a cup analogy again, alluded to earlier. So, we have this cup, there's an amount of energy that you have in a day in this cup some days, right? And every time you do an activity, your cup's gonna be less full.

[00:08:48] You're going to lose some things in the cup. And at the end of the day, if you've done too many things, your cup's going to be empty. But sometimes, let's say you didn't get sleep the night before. Let's say you did a ton of things the night before. You might wake up, not here, but here. So, you're starting off with less energy that day.

[00:09:06] So when you wake up and you say, oh, I don't feel as like I have as much energy like I usually do, take that into account and again, give yourself grace. Give yourself the kindness of, okay, today I don't have as much energy as I thought I would. I know I have to get X, Y, and Z done, but really prioritize.

[00:09:23] This is what I need to get done today. We touched upon this earlier, mood disorders, anxiety, depression, very common in neuroinflammatory disease. And I think there's multiple reasons for this. I think there's a direct effect of the neuro inflammation itself. Even if your MRI looks normal based on our conventional imaging, I think there's still inflammation that can still affect your mood and anxiety and depression.

[00:09:50] And then chronic disease. So, there have been studies in children with type one diabetes. So theoretically should not have anything, related to brain inflammation. But a lot of them are actually twice as likely to develop anxiety and depression as their peers because they are dealing with their chronic disease.

[00:10:04] Kids are smart, they know what's going on. And so just having the element of a chronic disease or the worries about even if you're a monophasic illness, a lot of my patients with a single attack, they still worry, am I gonna turn into a chronic disease? Is it gonna happen again? Psychotherapy can be super helpful.

[00:10:21] Support systems. A lot of us have support systems, which is great, but sometimes it's nice to have somebody who's external to your family and friends who you can talk to, and they really give you strategies. It's not just talking about your problems. They actually start having given you strategies of sort of things like reframing your thinking.

[00:10:37] When you have this situation that happens, how can you respond to it? Medications can be also helpful. I dislike the term psychiatric medications because that's how we group a lot of these treatments in there. But it's all related to brain chemistry. I liken to things like seizures. So, seizures happen when you have too much brain chemicals happening and it's overactive and then you start having symptoms because of that.

[00:11:01] Same thing with psychiatric symptoms. And oftentimes we're using the same medicines, for example, headaches and seizures and depression and/or anxiety. And it's all about balancing that brain chemistry is what we're doing. Sleep. I talked about good, some good sleep strategies, right? Like turning off your screens, your smartphones at least an hour before bed.

[00:11:23] And then the other thing about sleep to help you regulate your sleep/wake cycle is going to bed and waking up at the same time every day. This is true, even if you don't have a neuroimmune disorder, this is what they recommend. For those who have anxiety or depression. Going to sleep at the same time at night and in the morning is really important, even on weekends.

[00:11:42] Because that regular, having that regular circadian rhythm can help. For some people sunlight in the morning. So, whether it's going outside, opening windows, or phototherapy, they make these light boxes. Don't look at the directly into light box because that can damage your eyes. But having it on in the morning as you are doing your day, there's something about sunlight that really helps with mood.

[00:12:03] And so really do that, especially during the winter months when it can get dark pretty early. We talked about diet. So healthy foods and fruits and vegetables, trying to limit sugary foods. There's something

about sugar that can really affect mood for a lot of people. And it has to do with when you eat something sugary or caffeine, right?

[00:12:22] You have to get this instant high and for lack of a better word for that. And then you have this crash and that can make your mood symptoms worse. Again, exercise can help. Again, challenging, right? If you're having these symptoms, it can be hard to exercise but doing whatever physical activity you can.

[00:12:38] And then mindfulness. And again, vitamin D, there's lots of things about vitamins out there. A lot of people try to use vitamin to cure all these things. There's not a lot of evidence for most vitamins and I know I feel like I'm just touting vitamin D, but there is some data on vitamin D and depression and showing that for people who have depression and anxiety, vitamin D can help them.

[00:13:00] Another really hard to treat symptom is pain. Unfortunately, pain is one of those things that we can't really quantify, right? Like I can't do an MRI and say, okay, if you based on this MRI or this test or this blood test, you're gonna have X amount of pain. And unfortunately, that's one of the things that we have a hard time quantifying.

[00:13:18] It's what you are telling us as the patient is telling the doctor of what's going on. Going back to sleep, diet, exercise and mindfulness. I'm gonna take a step back with the sleep. This might sound counterintuitive, but I've experienced this myself as someone who doesn't have a chronic neuroinflammatory disorder.

[00:13:36] The days that I don't sleep, when I wake up, not only am I super tired, but I'm also cranky, I'm moody, I'm achy. I haven't done that much physical activity, but I just feel achy. And so, something about the sleep deprivation definitely makes my nerves be on edge. So going back to all of these lifestyle activities, it's gonna be really important.

[00:13:56] Therapies are helpful. So, there are certain physical therapy strategies that can help with pain. And then cognitive behavioral therapy the way that I think about it is mind over matter. And it's not to say that pain is all in your mind. That is not what I'm saying whatsoever. It's that you're having this pain, what are strategies that you can use using your brain to help accommodate that pain.

[00:14:18] We do use medications. I think medications are important. There are medications that you can take by mouth. There are patches out there, there's creams. Depending on who you go to, there's certain injections that you can also get. Treat all the symptoms, treat the fatigue, treat the insomnia, treat the anxiety, depression.

[00:14:35] A lot of these disorders also come with muscle stiffness that can also result in pain. And so, making sure that you're appropriately addressing the underlying potential cause for the pain. And there's alternative therapies that are available. So, things like acupressure, acupuncture, cold therapy. I've had some patients and families, I learned so much from my patients and families who explore other options.

[00:14:58] I'm always open to people exploring other options as long as we know it's safe, not gonna cause harm. And so, I've had some patients tell me, I have this incredible pain, but every day I do this cold bath and it's literally like an ice bath. They like fill up a tub, they put a whole bunch of ice in it, and then they sit in it for five minutes and that helps with their pain.

[00:15:15] I don't know if I could physically do that, but I think if you're in a certain situation, if you're in such severe pain that that's what works, that's what you're gonna do. So just there's different things about that. There was a question about brain fog earlier today. And what is that?

[00:15:31] What does that mean and how can we accommodate that? Again, very challenging, but if this all looks very similar, it's because this is common. This is a common way to treat that, sleep and naps. Diet, exercise, reminders, right? When people have brain fog, they're forgetting certain things throughout the day.

[00:15:48] Use your smartphone. I told you. Don't use your smartphone. Use your smartphone throughout the day, right? And have reminders. Use these tools to help you make lists, to help you remind you of things that you need to do. And then if you are able to, and your insurance covers it, go to see a speech therapist who can help you with a cognitive rehabilitation program.

[00:16:06] And then going back to our cup analogy, I think the same thing as physical energy, as mental energy. You are gonna wake up every day with a certain amount of mental energy. What activities do you have during the day? If you wake up with less sleep, do you start off with a lower amount of energy, mental energy than you would have otherwise?

[00:16:26] When is your cup actually empty? And what are your things that you can do to help with that? And again, going back to planning, prioritizing, pacing yourself. Finally, I'm gonna end with difficulty with urination. This can be uncomfortable for a lot of people to talk about. But this is also really important because this affects your life, right?

[00:16:46] If you're constantly having issues with bathroom related stuff, it's gonna affect whether or not you're able to go out and do activities or cleanliness and things like that. So, this difficulty urination can include both. Difficulty with starting urination, meaning hesitation to actually pee.

[00:17:03] I use "pee" a lot because I see kids, and then or actually having accidents. So, there's different ways to manage this. So first of all, we refer you to a urologist who specializes in bladder and urination to help with your symptoms. But there's some lifestyle changes that you can do. So, things like fluid management, so drinking fluids throughout the day and that way and avoiding large amounts before bedtime, so that way you're not having to get up in the middle of night to pee and also reduces accidents at night.

[00:17:30] Dietary adjustments. Limit bladder irritants. Again, I'd say don't, I didn't say avoid, limit amount. Things like caffeine in it. Coffee, tea, soda and alcohol. Timed voiding. So, if you're someone who has a ton of accidents for whatever reason, planned bathroom breaks, say, okay, and this is when we're younger and we do potty training, this is what you did, right?

[00:17:54] You planned okay. Every so often, whether it's every hour, every 30 minutes, every couple of hours, I'm just gonna go to the bathroom. And that can help prevent accidents. There can be different protective measures. So absorbent pads, there's adult diapers available, washable underwear, bring extra clothes for all of that.

[00:18:12] And then there's actually physical therapy. There are certain pelvic physical therapy exercises that can also help with urination. There are additional interventions when people are having difficulty urination. So, there's different medications. So, there's certain medications you can take by mouth that are called antimuscarinic.

[00:18:28] They help with the certain nerves that help with the, that affect the urination. And then things like Botox injections can also help with that. And then for those who have difficulty with actually initiating urination or having trouble with that, there's also different catheter ways of doing it.

[00:18:44] So some people can do intermittent self-catheterization where you actually take a tube, you insert it into your bladder, you drain it and you take it out. Versus for those who are unable to do that, some people will need surgery to have an indwelling catheter. And then there's some nerve stimulation devices out there that can help with the urination.

[00:19:01] And so with that we're gonna go ahead and move on to our panel. And then I just wanted to first off, see if there are any questions from the audience about symptoms. And this is our last major panel today. We have a few more things coming up and so if you have any last-minute burning questions, I think we'll be open and hopefully the panelists will be okay with this, of talking about anything, any other burning questions you have about your condition.

[00:19:28] **Audience Member:** It works. I say it works because it works with me.

[00:19:35] **Dr. Grace Gombolay:** I love that. Like I said, I learned from, or patients and families. So brown noise, it sounds like

[00:19:40] **Audience Member:** not white noise, but brown noise. I was just gonna ask the difference between the brown and the white. I've never heard of it.

[00:19:51] There's a difference in wave wavelength for this type of noises. They're called orange, brown, yellow, white for kids is recommended white. Okay. Is like more intense. Okay. What we have tried with my wife is brown noise. Okay. Is slower. Okay. And at the beginning sounds a little bit weird because it like a toilet, but no, sorry.

[00:20:22] In a toilet flushing. Okay. But have you heard, have you experienced a toilet over pulling, like coming at the beginning? It's like that. I only that that, my most comparison. Okay. But I found like that. Okay. But later on, we slept, it worked.

[00:20:45] Since I was diagnosed with transverse myelitis about a decade ago, I was advised about heat. And I am, I do have extra sensitivity. I just started one getting roughage in every day, which is your fruits and vegetables. I just called it roughage. So, I just try to always do a salad, that was the best way to do that.

[00:21:12] The other thing was to, oh, my brain just left me. When it comes to heat, or I'm driving in the car a lot, I was talking to some ladies at a booth, is I bought the hiking sleeves because I find, and now that if I'm in the car and the sun happens to be shining on the one arm, it just, it prickles at a different level than just regular.

[00:21:40] So the one hiking sleeve, which is just the sleeve that you buy them in pair. So, I just, but one works for me and that's just a way to mitigate the heat. But it also changes. I used to wear the cooling towels. Now that doesn't, I don't really find any help with that.

[00:22:01] **Dr. Grace Gombolay:** Okay. I wanted to ask our panelists, what are other tips that you have for our patients who are experiencing different symptoms related to their disease?

[00:22:12] **Dr. Diana Vargas:** The way that I like to phrase. As you talked about the cup, I usually, the way I think of it is we're, we are computers, right? We're all wired. We have our inner battery, which expires at the end of the day, and if you don't sleep, you don't get that battery charged full. And it's if you overheat a computer, it starts crashing, right? If you have a lot of windows on at the same time, things slow down. It's like you're

when you are, when you have these kinds of diseases that affect the brain, you're using a lot more energy just by one thought that somebody who does not.

[00:22:59] And identifying, coming to terms with the fact that you need to rest that brain, and if you don't learn to rest that brain, you're gonna have symptoms and resting that brain is not just sitting in a couch and thinking about all the concerns and all the worries. You're not resting your brain there.

[00:23:22] You're resting your muscles, but not your brain. So, learning to either sleep or disconnect your brain from situations that are making you think and think, it is very important. And if you learn different techniques throughout your life to, again, disconnect or charge yourself you are going to have a much better control of those symptoms that will come and go throughout your day and making you have more good days than bad days.

[00:23:54] And that's if you don't learn that, the disease is going to bug you every day, and it escalates and it becomes this huge ball of snow that keeps growing. And again, the only way that you're gonna be able to break that is again, reset things, go and charge yourself. And that's a way I like to look at things.

[00:24:22] Yeah,

[00:24:24] **Dr. Gabriela Bou:** a lot of the symptoms are managed specifically depending on what the symptom is. But I think that optimizing lifestyle as Dr. Gombolay had talked about and optimizing sleep diet trying to maintain a healthy diet and some level of activity, even if it's just a few times per week, I think that can help with a lot of the symptoms that you see with these neuroinflammatory disorders, like fatigue, brain fog, and pain as well.

[00:24:51] It may not necessarily take the symptoms away, but I think that it's a good, it's a good framework to start with, to help manage these symptoms as best as possible.

[00:25:01] **Dr. Grace Gombolay:** Great. And then I, another question that I get very often is what are your thoughts on the role of things like stimulants or medications to help with fatigue and brain fog and things like that?

[00:25:13] **Dr. Diana Vargas:** It's important to, so that it's fatigue can be so debilitating that you may not, you might have a normal exam. And one of the things that we encounter a lot is you can't work, you can't function. You are so tired and you have to file for disability, or you have to stop your job because the fatigue is so overwhelming.

[00:25:39] Even though you might have full strength on exam, for example. So, when we talk about fatigue, the first question I always ask patients is, how are you sleeping? Are you sleeping well or not? Because one of the biggest you know what most oftentimes, you're not sleeping well.

[00:26:01] And of course, if your brain is tired and you're going to take a stimulant that's going to try to make you even more awake, what's gonna happen? You end up crashing, right? And so many patients who have had a lot of issues with fatigue, they're not sleeping. They take one of these stimulant pills, they feel terrible.

[00:26:23] It's like all of your symptoms suddenly are starting to act up. You can't tolerate them. So, the first step is usually look at how you're sleeping. That should be the initial focus. If you are sleeping very good and you're basically, you're like, you know what? I'm sleeping 12 hours a day and when I wake up, I wanna still keep sleeping.

[00:26:44] It's not about not sleeping. It's the fact that I wanna sleep all the time. That's the type of fatigue where stimulants are gonna be effective because it's not about you not getting enough rest. It's about the fact that the fatigue is very predominant symptom being caused by the disease.

[00:27:06] And so usually the first thing I recommend is to try non-medication stimulants first. Okay? Try to use a little more coffee, try to use, try to exercise, things that are non-medications, because we have a limited number of medications that work. And what happens is over time your body gets used to them.

[00:27:29] And so if we start these very early on, there'll be a point where nothing is working, right? So, we wanna try to save them as when we really need them. So, anything that's non-medication, that's the first step. And then we go through a process of medications. We go from the milder ones to the more powerful ones.

[00:27:52] I usually say try to take some vacations on like drug-free holidays. So, as to try to help your body not get used to these medications so fast. But the key thing is how are you sleeping and if the fatigue is not getting worse because of lack of sleep. The other thing about fatigue is that there are really two different types of fatigue.

[00:28:15] You have mental fatigue and muscular fatigue. So mental fatigue is that fatigue where you wanna sleep the entire day and just, you can't focus. Your brain is very tired. The muscular fatigue is, you really feel like you've done a lot of exercise every day. Your muscles are they're heavy.

[00:28:34] You don't wanna even get off the couch because you're just, your entire body feels tired and heavy. And it's very important to make that difference because these types of stimulants that we give you will only really be effective for the mental type of fatigue. And so, if you're not clear on what type of fatigue you have and you take these stimulants, you're still gonna feel that muscles are tired and achy and it's not really going to be effective.

[00:29:02] And it's harder to treat muscular fatigue than it is to treat mental fatigue for that reason. And usually pacing yourself, and again, it's kind of like think of muscular fatigue as like, your inner battery gets wasted very fast. And so, you have to take multiple breaks throughout your day to charge that battery again to give you more energy throughout the day.

[00:29:27] **Dr. Grace Gombolay:** Okay. And then another question that I often get is, what is the role of CBD oil or cannabidiol oil? Now it's more readily available when you're driving down the street, you can see there's different CBD oil shops. So, what are your thoughts about that?

[00:29:44] **Dr. Diana Vargas:** So yeah, so CBD and even THC oil my, there are some patients, I have a number of patients on, both. The one thing that I tell patients is that one, you can get it everywhere, but it's not really regulated. So, you don't really know the dosage, the amount you're getting, what it is that you're getting.

[00:30:12] And so that can be a little tricky because the idea is not also to have you be having difficulty functioning and having, the THC affect your perception. The other thing is, the other thing I warn patients about is if you are having a lot of cognitive problems and difficulty with brain fog and, thinking, the chronic use of THC and to a lesser extent CBD, have been shown to be causing some more negative effects on cognition.

[00:30:45] And so you really wanna be, if it's a very big issue for you, you really wanna try to stay away from it. It really helps with spasticity; it helps with chronic pain. If you find that something like CBD cream helps for nerve-related pain, use it, it's not gonna be absorbed into your bloodstream enough to give you any other issues.

[00:31:07] So anything that's solution-based or not really medication you're taking has fewer side effects. And so, if it works, that's great. If it doesn't work well, we'll find something else that does. And with the THC, again, the most important areas where I feel like it may be effective is for spasticity, spasms, and for pain as well. But you have to be careful with the dosage.

[00:31:38] **Dr. Gabriela Bou:** It's not so that THC and CBD products - we don't have very good studies on them to really measure what it is that they are helpful for. What are the, we have some idea of some of the general risks, but we don't have it very well fleshed out in studies.

[00:31:54] So it is something that I think, especially if we've tried lots of different strategies in terms of lifestyle modifications or medications, and then none of those things are really working very adequately, then it's something that, as Dr. Vargas had said, may wanna be tried with caution for pain spasticity but keeping in mind that it may worsen some other symptoms like some of that brain fog.

[00:32:21] **Audience Member:** it's actually not so much a question. I was thinking when you were talking about the CBD oil, I have transverse myelitis. Like I said before, I can't believe how many people, even sometimes it feels like a random stranger always wants to tell me that "Oh, have you tried this cream? Oh, this will help you."

[00:32:42] I've had people at work bring me little containers, oh, you need to try this will help you. And it's so strange. I appreciate, I know that their heart is in the right place, but it's frustrating. I have it where my brain can't communicate with my quad muscles. And the number of things people have wanted me to spread on my thighs is a little disturbing.

[00:33:07] But nothing, it doesn't change anything. And so, it's gotten to a point now where I think, do I be honest with the people and just say I appreciate it, but nothing changes this for me. But it's just funny how many people just genuinely think that they have something that's going to somehow cure you.

[00:33:31] The other thing I was gonna say with fatigue is that I can have it where I have mental and muscle fatigue at the same time because when I walk, I've tried to explain to people when, normally when you walk, you don't have to think about it. And now, whatever I'm doing, I have to put a lot of thought into it.

[00:33:53] I have to really put a lot of focus on it, that is very fatiguing. And so, it is one reason that I'm very grateful for my scooter because it does help with the fatigue management because if I were to walk and walk, it is just exhausting. And like I said, mentally and physically. So last year when I was in Dallas for the medical conference, I was so grateful when somebody said, don't feel ashamed to use a scooter for fatigue management, because there are a lot of people where that makes a major difference in their life. And for me it has. And so, I'm very grateful.

[00:34:38] **Dr. Diana Vargas:** Yeah, and I just wanna add that you have to find ways to live with the disease you have, and you should not limit your life because of the disease you have. You have to figure out how you keep doing what you're doing despite of the disease you have. And so, we live in an era where we, where there are scooters, where there are things that you can do to keep doing the things you're doing.

[00:35:16] And there are, and sometimes it's very hard to make that step. And I usually tell patients because yes, when you sometimes are going to make, I don't wanna use this because if I start using this, I'm never gonna be if you're weak... I'm gonna get used to this,

[00:35:34] And then I don't wanna, I don't wanna exercise, I don't wanna walk. And it's a conversation that it, that we have. And it's important to realize that it's, if you want to keep walking, you're gonna do it. It's your

willingness to do things. But if you don't, you're not going to go to the grocery store because just the thought of it just makes you so tired,

[00:36:02] Then you're living every day making those choices and you end up not doing the things you wanna do because of that thinking of all the things you need to do to get this one thing done, right. And so, knowing that there are ways that you can do things, and a lot of times it's a conversation with your doctor, I need a tag for the car.

[00:36:28] You don't have to walk all the steps in order to go to where you need to go. Or you know what, I just take that scooter in the grocery store so I can get my shopping done. Or it just requires maybe more coordination of things. But I always say, don't let this disease make it so that you don't do the things you need to do or you wanna do,

[00:36:54] because it's every decision you have in your life, yes, you have to take into account that disease you have, but it just forces you to work around it. Always try to work around it. Don't stop doing what you wanna do in life because of this.

[00:37:15] **Audience Member:** A quick question, do electrolytes, is there a benefit in terms of getting more electrolytes in terms of hydration as well? Then is there a difference between the regular water and the water that they say with the alkaline? Is that helping? Am I making this up? Is that their marketing and advertising?

[00:37:39] **Dr. Gabriela Bou:** Electrolytes would be helpful if you are super dehydrated or you've been out, you've been out, you've been active, you're very dehydrated, it can help you hydrate faster. It, as far as we know, we don't know of any specific benefit of having water with electrolytes in patients that have these neuroinflammatory diseases. But in general it can help with hydration if you're dehydrated from a lot of physical activity or being out in the heat, whatnot.

[00:38:07] **Dr. Diana Vargas:** Yeah, I usually say if you're supposed to be getting your electrolytes from your diet right, from the food you eat. But if you are in general, if you're eating a balanced, healthy diet, you should be getting enough electrolytes that you don't need a supplement in water.

[00:38:24] But sometimes more so in these types of diseases where your muscles are very sensitive and you might get a lot of spasms after exercise, for example, taking one bottle with electrolytes might make a difference. If you're not getting enough electrolytes in that food that you're eating.

[00:38:47] So let's say that you're gonna go and do a little bit of exercise and you eat a banana or crackers before you do, so you're getting there, your potassium, your sodium, you don't need that, those electrolytes but if you are not having those things in your diet right after, right before you're gonna do exercise, for example, you might need some electrolytes. It might make you feel a little better after.

[00:39:10] **Dr. Grace Gombolay:** And how about the alkaline water question?

[00:39:12] **Dr. Diana Vargas:** The alkaline water, at least to my knowledge, serves no purpose.

[00:39:20] **Dr. Grace Gombolay:** They are marketing that in the store, so yes.

[00:39:26] **Audience Member:** From the hydration perspective, I just wanna say again, I don't know the science behind this or this, I don't know if there's any studies around this, but I do have some patients that receive weekly hydration treatments, and they get hydration before and after their IVIG treatments.

[00:39:41] Some of those patients have switched from normal saline hydration to lactated ringers, which does have some electrolytes in it. And they have said that they do feel better with the lactated ringers versus normal saline. So, I don't know if that's something you wanna discover, explore with your physician, but that's out there too.

[00:40:03] **Dr. Grace Gombolay:** Great. Thank you so much to our panelists and thank you all for participating.