

# Identifying and Managing Fatigue

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[00:00:00] **Roberta Pesce:** Our next talk addresses fatigue, brain fog and drowsiness, which many people with rare neuroimmune disorders experience on a frequent basis. I am joined by Dr. Sara Qureshi, a neurologist of Billings Clinic, who will address what causes fatigue, and provide some treatment strategies for managing it. Hi, Dr. Qureshi. Welcome, and over to you.

[00:00:27] **Dr. Sara Qureshi:** Thank you, Roberta. Hi, everyone. Thank you for giving me the opportunity to talk about fatigue today. So just very briefly about me, I trained in rare neuroimmune disorders in Dallas, and for the last 6 years I've been running a rare neuroimmune disorder clinic here in Billings Clinic in Billings, Montana, and fatigue is something we see in our clinic all the time, and so what we're going to talk about today, we do all the time in our clinic, and I'm sure most the audience here somehow, some patients or caregivers know quite a bit about it. So, no disclosures relevant to this today for me.

[00:01:16] And here's the list of some of the symptoms that we see in our patients with rare neuroimmune disorders. So, it's a long list of symptoms, there's actually more than the ones just mentioned here. And you can see fatigue makes it to our list, and it's something we commonly struggle with and manage, and minimize its impact on life. The interesting thing about fatigue is it's an invisible symptom, so it's often hard to understand for the patient themselves in all its implications, and it's hard to explain to well-meaning people including family members, friends, coworkers, it's got a very wide range of effects as we'll talk today.

[00:02:05] And in terms of reasons for fatigue, we'll talk about primary and secondary fatigue, and then we'll talk about fatigue mitigation strategies to mitigate its impact on life, and at the end we'll just go through a typical clinic case in managing fatigue. So, fatigue is extremely common in rare neuroimmune disorders. I hardly ever see anybody who doesn't have it. Although if this was not a virtual talk and I asked everybody in the room to raise their hands who've experienced fatigue, then probably everybody including me would raise our hands.

[00:02:46] So everybody usually experiences some fatigue in their life, but in neuroimmune disorders people tend to have very intense fatigue, which interferes with daily activities. It is often refractory to rest, you could be getting a very good night sleep but still very extremely fatigued, and a lot of people say it's worse later in

the day. They say it's worse when it's more hot or humid or when they're stressed out. Also, we were listening to the really good talk of bladder management before mine.

[00:03:19] A lot of times it's a sign of infection as well, the previous speaker was mentioning that sometimes you have bladder colonization and it's hard to know when you have actual infection or when the bacteria are just sitting in the bacteria doing nothing. So, one of the signs of a bladder infection is that the fatigue can be worse, and other neuroimmune symptoms like muscle weakness, mobility issues, spasms can also be worse. Sometimes that's the only sign of a bladder infection because the bladder might be numb, and people may not have the burning.

[00:04:03] So how do people normally describe fatigue? A lot of people will say it's more physical or more mental or both. Some people describe it as brain fog. Roberta was mentioning that just now. Some people describe it as feeling like when it's more physical that their arms and legs are out of proportion to the weakness from the disease itself. They feel like they're concrete or made out of lead. Some people describe fatigue as the same kind of feeling that everybody else might have if they have a flu, except when we have a flu it's short-term thing and everybody understands, but when you live with it all the time if you don't explain it to others then they don't understand.

[00:04:54] So fatigue is just one word but it kind of goes on to impact a lot of things. It's often very misunderstood, even by the person experiencing fatigue, and definitely by other well-meaning people. So, the person experiencing the fatigue, if they don't understand that this is what it is, they can feel a lot of guilt a lot of times because they're not able to say, contribute as much at work or at home, or not be able to keep up in social activities, so there can be a lot of guilt associated with it. Fatigue can also make all the other symptoms like mobility or visual issues worse as well when the person is more fatigued.

[00:05:42] In terms of the people around the person experiencing fatigue, if they are not well educated about it, they can sometimes misunderstand even though they're well meaning, and they can think the person is being lazy or they're irritable or maybe they're angry at us, they're not engaging and talking, or engaging emotionally. So, fatigue can often be perceived as mood issues as well. One big implication is the brain fog or slow processing speed, so a lot of people can have word finding difficulty as well. So, this kind of public speaking often causes a lot of anxiety if your fatigue is causing word finding difficulty. So, a lot of people at work will get much more anxious about public speaking, et cetera.

[00:06:33] Some people even perceive this as cognitive issues, and they can feel like they're having cognitive issues. So, it's very important to understand fatigue and communicate it to relevant people, and of course work with your health care team to mitigate and minimize its effect on life. A lot of times I will encourage my patients to bring in family members so I can explain to them my experience with so many patient's fatigues, and that usually helps.

[00:07:10] If we divide fatigue into two main categories, which we'll do here, primary fatigue and secondary fatigue. We do think in autoimmune and rare neuroimmune disorders for sure, there is a primary fatigue which is directly related to the disease. It's not very well understood, and it's probably related to the central nervous system inflammation and damage. So, this type of fatigue, to manage these medications can be considered, but it's very important to first look at the whole clinical picture and see what could be contributing in terms of secondary fatigue.

[00:07:48] So a lot of times in almost everybody who's experiencing fatigue there are a lot of other things than the disease itself. A lot of times people, for instance with spinal cord inflammation, will have sleep interruption due to pain, spasms, or bladder issues, having to get up and go to the restroom many times a

night, so those things can interfere with sleep. A lot of times the medications we use to address some of these symptoms, like especially pain and muscle tightness, these medications can cause drowsiness during daytime. Medications for mood and sleep can cause drowsiness during daytime.

[00:08:33] People can have depression not directly related to their medical condition which can cause interference with sleep. People can have a primary sleep disorder totally unrelated to the neuroimmune disorder. For example, sleep apnea or restless legs, that can interfere with sleep, and it can cause drowsiness or fatigue during daytime. People can be fatigued in ways that are not directly linked to sleep at all. People with ambulation or mobility difficulties, they have a lot more work to do in getting from point A to point B, and I've not.

[00:09:17] It's a very fortunate situation, not a great example, but I've been on crutches for 4 months of my life, and by the time I would get to my office I would be so tired that I would feel I would need a nap. So, people with ambulation difficulty, they have a lot more work to do in getting from point A to point B. So, looking at that and optimizing that part of the picture as well helps with fatigue. And then often times people will say fatigue is worse if it's hotter, more humid. Like I said before, infection, if somebody has a temporary worsening of fatigue, I'm often thinking of a hidden urinary tract infection, which is silent otherwise.

[00:10:02] And then inactivity stress, poor diet, that can cause fatigue in all of us. It's also very important to remember sometimes we get too zoomed in on our part of the specialization, I specialize in neuroimmunology, it's very important for me to remember that my patients could have something else totally unrelated, like anemia, thyroid issues, or sleep disturbance from menopause, that could be contributing to fatigue. So, before we prescribe medications for fatigue, it's very important to look at the whole picture, which is very complex usually, and usually there are more than one thing that we can find.

[00:10:44] Okay, so in terms of fatigue managing strategies we aim to identify and mitigate the multiple underlying factors in each individual that are contributing to that particular person's fatigue, and then we must re-evaluate periodically because the situation changes. Something else could be in the picture now, and if we're looking, not re-evaluating constantly we could miss it. So once the underlying factors for this secondary fatigue are addressed then we consider cautious use of fatigue medications.

[00:11:18] So after different secondary fatigue issues that I mentioned, this is how we try to mitigate them. So, if somebody has fatigue or drowsiness from medications for nerve pain, muscle spasms, mood issues or sleep, we try to avoid these sedating medications during daytime. Or sometimes we cannot do that, but we at least lower the dose of these medications during daytime, and sometimes we increase them at nighttime to make sleep less interrupted by pain or spasms. We also often get help from urologists to help us with managing bladder better so people are not having interruptive sleep due to that.

[00:12:08] Often times we also encourage people not to rely solely on medications for muscle spasms, because stretching doesn't make you drowsy, medications to help muscle spasms often make you drowsy, so we want to have a more holistic approach and encourage things like stretching, so at least you can lower the dose of medications that can cause muscle spasms. Sometimes, for instance, one of the big reasons for using baclofen pumps is that they allow lower dose of medications for muscle spasms and people have less fatigue, as opposed to oral medications for muscle spasms.

[00:12:51] Also if we find anybody has depression or sleep apnea, we address that, and depression or anxiety can, again, not just be managed by medications because medications have side effects, we encourage counseling, we encourage good sleep hygiene as well. Not trying to address everything with a medication, because those have side effects, and one of the common side effects is drowsiness. It is very important to

work with a physical therapist or physical medicine and rehab to decrease the work of ambulation and mobility, so the person is less tired when they get to where they need to go. We often look at work accommodations, home accommodations, parking in the closer spots so there's decreased work of ambulation or mobility.

[00:13:45] We also encourage and a lot of people, patients are the best at doing that, is making sure there's not heat and humidity around them, utilizing cooling techniques and working on trying to remain active. For most of us, whether or not we have a neuroimmune disorder, if we are active there's less fatigue. If we are getting a good night's sleep, a good diet, there's less fatigue. And periodically we check for thyroid issues, vitamin B-12 deficiency, anemia, those other conditions that could cause fatigue.

[00:14:21] So there are medications for fatigue, fortunately, and they're quite widely utilized, but the important thing is to make sure we're not missing secondary reasons for fatigue and not addressing those, because medications can have side effects. There are three typical categories of medications used for fatigue, amantadine, the narcolepsy category of medications like modafinil or armodafinil, and then the amphetamines. It is important to use these medications very cautiously because they can have side effects. Common side effects are interfering with sleep, so that would add to the problem. Palpitations, high blood pressure. Every now and then I see somebody who gets irritable on these medications, so it's important to use them with your health care provider cautiously, at the right dose, at the right time, in a way that they help you and not add to the problem.

[00:15:24] Good sleep hygiene, healthy diet and exercise are equally important in people without neuroimmune disorders and people with neuroimmune disorders, and they make a huge difference. Work accommodations are extremely important, so we often work with our patients, and usually will write them letters to help them with flexible work hours, regular rest breaks, making sure they're closer to the restroom so there's less work of ambulation or mobility if they have to go to the restroom again and again. Making sure they have good parking spaces, that adds up and it could be the difference between allowing somebody to work efficiently or not.

[00:16:10] Home accommodations are extremely important as well. A lot of times it takes a village to manage somebody with a neuroimmune disorder, and very important people on our team are occupational therapists and physical therapists, and they help. I've had really good feedback from patients for sending people to occupational therapists or physical therapists with the goal of making their ambulation or mobility more efficient and working with them to manage fatigue.

[00:16:45] So this is an example of a 32-year-old patient with neuromyelitis optica spectrum disorder who reported fatigue in my clinic, and we looked at all the reasons for secondary fatigue, drowsiness by pain and spasticity medications, interrupted sleep due to nerve pain and spasms, bladder issues, interrupted sleep due to restless legs, and of course lack of exercise, sleep hygiene, and then we found an underlying thyroid disorder. So, we worked at decreasing daytime dose of medications that cause drowsiness, stretching regularly to decrease muscle spasms, increasing nighttime doses of pain medication for a better sleep, refer a note to urology to address bladder issues, and treating the underlying thyroid disorder.

[00:17:32] And then a few months later she was still having fatigue, so we cautiously started fatigue medications, and periodically re-evaluate it to make sure fatigue is optimally managed and we're not missing anything else. Ten years later the same patient can come in with now symptoms that are suggestive of sleep apnea, causing a lot of daytime fatigue, and in that case, addressing that issue helped. So, fatigue management is a dynamic process. You continue to look for new reasons for fatigue or what strategies you're using if they're working anymore or not.

[00:18:12] Fatigue management also helps brain fog, word finding issues, cognitive issues. Allows a person to function better in every capacity. And it takes a whole multidisciplinary team to manage fatigue, and really all of the symptoms that people with neuroimmune disorders experience, and here is some of that team in Billings Clinic. Thank you.

[00:18:38] **Roberta Pesce:** Thank you so much, Dr. Qureshi. This was an incredibly helpful talk. We don't have time for any questions unfortunately, but I really wanted to convey that one of our community members just shared that this presentation was tremendously validating for the fatigue that that person struggled with, so thank you so much for being here and giving that talk.