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### Evaluating and Promoting Health in Idiopathic Hypersomnia: Beyond Sleepy

#### Announcer:

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#### Dr. Schneider:

Welcome, and thank you for joining. I'm Dr. Logan Schneider. I'm a Sleep and Cognitive Neurologist, and I'll be talking to you today about how you evaluate and promote health in your patients with idiopathic hypersomnia, recognizing that it's not just about how much they're sleeping.

And to begin with, obviously, we know idiopathic hypersomnia when we see it. There are a host of symptoms that really define the constellation of this condition, really more of a syndrome than just a sleepy patient. The common ones obviously being the chief concern is the excessive daytime sleepiness, but also the excessive need for sleep is often a hallmark of these patients, as well as sleep inertia, the inability to really wake up and be ungroggy, despite having had often adequate amounts of sleep, if not excessive amounts of sleep. And this can also pertain to not just the main sleeping period, but also naps that are quite frequent and often long, is often why patients describe not wanting to go to bed because they know that they're not going to wake up feeling refreshed like you or I. As well as the concept of brain fog, where neurocognitive dysfunction is something that really pervades every minute of their day.

And so, this is why we can't just be assessing with the excessive daytime sleepiness scale of the Epworth Sleepiness Scale score, nor can we just rely upon our neurodiagnostics to be able to give us an answer because they weren't designed for this. So, helping support that clinical impression are things like questionnaires like the Idiopathic Hypersomnia Severity Scale, which really do a great job of helping patients report their symptoms, quantify the severity of those symptoms, as well as the multidimensional nature of those symptoms. So, the Idiopathic Hypersomnia Severity Scale is a great tool that you can use to understand the holistic characteristics of the main components of this disorder.

But let's also recognize that there are other parts of how this is affecting patients' lives, including dysautonomia, or dysfunction of the autonomic nervous system, as well as quality of life impacts that also should be discussed with patients and assessed on a regular basis.

Just looking here at the autonomic dysfunction, we see that certainly patients with idiopathic hypersomnia seem to have more autonomic dysfunction, higher prevalence of autonomic disorders like POTS, as well as higher rates of symptoms in categories like orthostasis and vasomotor symptoms. And it's the severity of these symptoms and conditions that seem to associate with their excessive daytime sleepiness, their levels of fatigue, as well as their quality of life. And so, this is yet one more piece of this puzzle that we should be asking about and assessing in our patients.

And beyond that, obviously, once we've taken care of, or at least are working on the primary symptoms for our patients, we should also be considering more of that holistic care for our patients. We're not just their sleep doctor, but we actually are their clinician caring for them as a whole. And noting that there is higher prevalence of cardiovascular disease, cardiometabolic disease, and undesirable cardiovascular outcomes like strokes and heart attacks, we should certainly be assessing and addressing these risks and trying to

mitigate them when possible.

And this is based on data that looks at the population as a whole, looking at claims data comparing those folks with idiopathic hypersomnia to a number of matched control individuals who have matches on demographic data, region, payer, trying to control for all of the factors that might influence increased cardiovascular risk, and really hone in on it seems that idiopathic hypersomnia is in and of itself associated with a higher risk. Now, we don't exactly know why. It could be underlying common pathophysiologies, it could be the consequences of idiopathic hypersomnia, it could even be contributing to idiopathic hypersomnia symptoms. But nonetheless, it certainly highlights that it's important to assess and address this.

Beyond obviously, our mainstay of treatment, which is managing the patient's, you know, schedules and behavioral aspects and even the cognitive reactions that might occur, emotional reactions that might occur in response to the disease, but also using our bag of medications that we at least have been supported in using for several decades. And now the certainly the FDA approved treatments that we have, that demonstrate great efficacy in these patients. But if you look at the American Academy of Sleep Medicine data, you can certainly see how they've synthesized the impact that various medications can have on the main symptoms and issues that these patients are experiencing. And you can decide for yourself through shared decision-making with the patient on what is the most appropriate treatment; granted, recognizing that there is only one FDA approved treatment for this condition at this time.

And that medication in the oxybate class of medications certainly doesn't lend itself naturally to understanding how it can improve excessive daytime sleepiness or any of the symptoms of idiopathic hypersomnia. But I contend that it is something that we're familiar with; you have fragmented sleep, and if it's making you sleep more soundly, then potentially maybe that's the mechanism by which it's working. And this is what we do as sleep doctors, we improve sleep to improve daytime function.

A great example of that, look at the fragmented sleep on the left and how it improved on the right. This is what we do with PAP. So, our job of treating sleep, to improve sleep, and therefore improve wake is not all that counterintuitive, but I think we still have yet to discern what exactly that looks like from the standpoint of how our treatments improve the lives of patients with idiopathic hypersomnia.

So, I hope this is a little bit of food for thought, inspiring curiosity as well as understanding of how these medications might be helping our patients and how we can address their whole care.

**Announcer:**

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