GBS | CIDP Foundation International

Speaker Series Summary Episode 10: Fatigue

Overview

In this Speaker Series episode, we talked with Dr. Stojan Peric, a researcher and professor, at the University of Belgrade in Serbia and a neurologist at the Clinical Center of Serbia. Catch up on the conversation with Dr. Peric and learn what fatigue is, how it is triggered, and how it can be helped.

Summary

An Update from Our Patient Registry	**According to our patients dealing with GBS, CIDP, and MMN:** • 68% say fatigue interferes with physical functioning • 72% say they are bothered by fatigue and how they feel physically • 75% have trouble finishing tasks of fatigue Learn more about our patient registry by visiting: www.gbs-cidp.org/research/gbscidp-patient-registry/.
What is fatigue and how is it different from being tired?	Fatigue is not normal but pathological. It is exhausting. It is the lack of energy that is present not only after activity, but presents continuously. • Pathological: indicating a disease, not the disease itself, but the science of the disease Tiredness is normal and can happen to everyone especially after a long period of physical or mental activity. You can completely restore yourself with rest; it is not continuous.

Why does fatigue happen?	**There are two types of fatigue:**
	
	1. Peripheral: the impairment of peripheral nerves can cause fatigue
	2. Central Nervous System (CNS): personality, life experiences, reactions to stress, and/or post traumatic experiences can induce fatigue
	  ◦ Fatigue happens mostly in chronic diseases, but will occur in acute conditions like GBS
	  ◦ Fatigue is subjective and not always biological
	  ◦ Depression, anxiety, and a lack of proper sleep can all contribute to fatigue
	  ◦ Can not be objectively measured, similar to pain

Does inflammation contribute to fatigue?	Yes, inflammation contributes to fatigue, especially non-neurological conditions like metabolic syndrome. • For chronic conditions: inflammation contributes to cytokines that affect our brain, muscles, and body that cause fatigue
Do you think being more mindful and thoughtful about movement can contribute to exhaustion and feeling fatigue?	• It is not always related to impairment or muscle weakness. • Less activity does not mean less fatigue because physical activities can decrease fatigue like aerobic exercises. • Be active!
What is the FSS scale?	It is the Fatigue Severity Scale (FSS) comprised of 9 questions aimed at trying to quantify fatigue levels. Originally, it was made to study sclerosis. So, the RUSH FSS was made to compare different inflammatory neuropathies. Yet, both are used for looking at the epidemiology of the disease.
Is there a biomarker for fatigue? Or a test to determine the level of fatigue?	• There is no biomarker for fatigue. • Yet, for some conditions an EMG is performed to measure the amplitudes of motor potentials as a measure of fatigue such as Myasthenia gravis ◦ But an EMG is currently not used to measure fatigue in CIDP and MMN
Why does fatigue come and go with other symptoms?	• The change in ability and weakness are not correlated with fatigue. • Fatigue is not a measure of disability because it can come and go.
Why do patients experience fatigue after Ig therapy?	• Fatigue should not be an indicator of increasing or decreasing Ig dosage. • In addition, if a patient is treated with Ig for too long, their fatigue may increase. • Ig treatment should be determined on an objective measure of disability and weakness. • Lastly, the absence of fatigue does not indicate a green light to stop Ig therapy!

How can you help fatigue?	**Here is are a list of methods to help with fatigue:** • Exercise such as swimming and cycling • Cognitive Behavioral Therapy • Anti-Depressants • Reducing Alcohol and Caffeine • Patients with other metabolic conditions like diabetes should work to improve their other conditions because it will also improve their fatigue
Does long COVID increase fatigue?	It is possible that covid can produce this condition, but it is not correlated to fatigue.
Does Human Growth Hormone (HGH) medications help decrease fatigue?	“I cannot recommend this to anyone because we don't know if it is efficacious, and we do not know if it is safe for this patient.”
What are some therapies in clinical trials that can help fatigue?	• Most clinical trials measure disability and weakness rather than fatigue because it is less measurable. ◦ Disclaimer: There is no guarantee that fatigue will not completely go away. • FCN blockers and Complement inhibitors are currently being researched and could possibly help.
Are there any medications and supplements that can help fatigue?	There are no specific drugs to treat fatigue, yet some medications can induce fatigue. So, be cautious and consult your doctor before taking any medication.
Are there any dietary solutions to treat fatigue?	• The Mediterranean diet is always good for any condition! • Rice and fish are good foods to protect from developing inflammation

How do patients effectively communicate fatigue to their physician?	• Keep a diary of the different events where fatigue occurred while recording the level of fatigue to compare. ◦ Journaling can help you understand how fatigue may be induced. • Explain your stress, sleep habits, and medications that can impact fatigue. • Explain what you are missing, such as obligations or social activities, to provide a wholistic perspective.
For care partners, what is some advice to help patients dealing with fatigue or at least manage fatigue?	• There is no official data to answer this question. • Yet, giving social support has been proven to impact a patient's quality of life. • "One piece of advice I have is to encourage them to be active and do different things rather than sitting at home thinking about their disease."
What is the link between mental health and fatigue?	While both the physical and mental condition of patients are affected, depression, anxiety and other mental illnesses can negatively affect fatigue. I would recommend seeing a psychologist.
One of the hardest issues with being active is starting tasks; what do you recommend helping patients get started?	• I would recommend starting very slowly and then increasing their level of activities very slowly, especially those with significant weakness. Physical therapy is definitely a solution. • Results will be long term and not immediate.
Does aqua therapy help?	• Yes, because you are able to do more movements in water than on land. • Hot water is not good because it can cause inflammation and can worsen a patient's condition. So aqua therapy is good with cold water.
Does acupuncture improve fatigue?	I cannot be sure, it should be tested, yet it helps with pain.

Do hyperbaric oxygen chambers help improve fatigue?	There is no evidence that this can help. I believe that extra oxygen can produce oxidative stress and become problematic for cells.
Is it common for people with GBS to experience fatigue over 10 years after their diagnosis?	• Some patients can have some residual neurological deficit, so not everything was improved after the acute phase of GBS. • Even patients with no pain still report having fatigue. Some papers report that 40% of patients with GBS have fatigue after 20 years. • These conditions are life-threatening, so it is real trauma, making the psychological component important to one's fatigue.

Relevant Resources

Share Your Experience with Fatigue and Your Condition in Our Patient Registry

Access our Community Connections page here to find more webinars and events