GBS | CIDP Foundation International

Speaker Series Summary Episode 18: Aging and Guillain-Barré syndrome: Understanding Typical Aging vs. Residual Effects of GBS

Overview

In this episode of our Speaker Series, we dive into what a person might feel as a result of GBS residuals and what that person might feel is normal aging, how to tell the difference, and what to do about these symptoms with University of Pennsylvania neurologist Dr. Chafic Karam.

Summary

Introduction	**Dr. Chafic Karam completed his neurology training at Beth Israel in New York City, and did a neuromuscular fellowship at Harvard and peripheral nerve pathology fellowship at the Mayo Clinic. Dr. Karam is currently a neurologist at University of Pennsylvania where he treats patients in the amyloidosis center and in the peripheral neuropathy clinic at Penn. He directs the fellowship programs and does clinical research on neuropathy and amyloidosis., and is a member of the Foundation's Global Medical Advisory Board.**
What are residual symptoms of Guillain-Barré Syndrome (GBS)?	• **Residuals occur as a result of nerve injury from GBS, similar to the way that a storm leaves damage behind.** • **Numbness, tingling, weakness, and pain are common residuals that may improve with time but never vanish entirely.** • **Unfortunately, there is no treatment or medication to grow nerves back but there is medication to manage symptoms**

How much nerve regrowth is possible after GBS?	• **Nerves regenerate at about 1mm per day.** • **Proximal muscles (those closer to the body) recover faster than distal muscles (ex. hands/feet) because the body of nerves live in the spine; the ones farther away from take longer to recover.** • **Most recovery occurs within two years of the onset of GBS symptoms, with minimal improvement expected beyond that.** • **Nerve recovery is not perfect but still possible.**
When is a symptom considered a residual from GBS?	• **If symptoms persist beyond two years, they are likely permanent residuals rather than ongoing recovery.** • **Incremental recovery is not always noticeable to the patient, but may be noticeable to the physician using regular objective, measurable tests.** • **Those with severe cases of GBS may need more time to recover from their symptoms.**
How can residual pain from GBS be managed?	• **Types of pain GBS patients can experience: Burning sensations, electrical shocks, deep aching pain, allodynia: light touch that causes pain.** • **Medications like gabapentin, pregabalin, or antidepressants (e.g., duloxetine, nortriptyline) may help.** • **Common side effects can include drossiness or swelling of one's legs. To combat these side effects, lower dosages may be favorable.** • **Topical treatment (lidocaine, ketamine creams) or alternative therapies (acupuncture, massage therapy) can provide relief.** • **Some patients use compression socks or other sensory exercises.** • **Suzetrigine, is a new non-opioid pain medication that was approved for acute pain and is not being studied for chronic neuropathy (off label).** • **Opioid medications only provide a short-term solution to pain because the dosage of treatment will need to increase to maintain the same effectiveness over time** • **Pain management may take a team effort to treat!**

Is fatigue a common residual symptom of GBS?	**Yes, fatigue is a complicated symptom that can result from extended hospitalization, nerve damage, deconditioning, and other health factors.** • **Managing fatigue requires improved physical conditioning gradually.** • **It is important to treat other medical conditions first before trying to treat fatigue.**
How can a patient protect themselves from muscle wasting?	• **Exercise and physical therapy are very effective.** • **Electrical nerve stimulation has been explored, but its results are varied and inconclusive.** • **Recovery is a slow process that requires you to listen to your body and an understanding of what your body can tolerate.** • **Managing pain and sleep can help manage the intensity of fatigue.**
Does GBS increase the risk of other diseases later in life?	• **There is no known link between GBS and increased risk of conditions like heart diease or cancer. However, chronic neuropathy may lead to secondary complications such as arthritis in the hands and/or feet.** • **Consult your neurologist if you experience significant changes in your body; you should always be**
Does GBS reduce your lifespan?	• **While the initial acute phase can be life-threatening, long-term survival is generally unaffected unless you experience complications such as respiratory failure, infections, or difficulty swallowing that persists.** • **About 5% of GBS patients pass away from their condition or complications related to the condition.**
Are there long – term effects from being on a ventilator due to GBS?	• **Some patients may experience scarring, phrenic nerve (which helps breathing) damage or vocal cord issues from intubation.**

How can someone distinguish between a new neurological issue and a GBS recurrence?	• Any new or worsening weakness and loss of function show be evaluated by progressive symptoms could indicate CIDP or another condition like Parkinson's disease. • Those with Parkinson's Disease experience resting tremors, unsteadiness, freezing, etc. Therefore, a neurologist will be able to distinguish a new muscle disease from GBS and Parkinson's Disease. • Always talk to your doctor about any new symptoms or concerns that you may have.
How does GBS affect mental health in the long-term?	• Many patients experience PTSD or anxiety. A strong support system, including an understanding physician, support group(s), and professional mental health care is crucial.
Can GBS reoccur? How can one prevent it?	• Recurrence is rare. If it happens multiple times, it may actually be CIDP. • There is no clear way to prevent recurrence. • Some patients worry about vaccines triggering GBS, but the risk is low. Therefore, identifying a treatment or event as a trigger for GBS may be extremely challenging and inaccurate. • It is more important to stay healthy overall, and seek mental health treatment if GBS recurrence anxiety is affecting you.
How does GBS affect mental health in the long-term?	• Many patients experience PTSD or anxiety. A strong support system, including an understanding physician, support group(s), and professional mental health care is crucial. • The GBS|CIDP Foundation International has many resources to help connect patients with support.
Is anesthesia safe after GBS?	- Generally, yes, unless the patient has a lung function impairment.

Does neuropathy worsen with age?	• **Everyone ages at different rates where our organs shrink including our brain, nerves, height, etc.** • **Neuropathy does not necessarily worsen with age, but aging itself causes nerve degeneration which can contribute to increased symptoms.** • **Do not use "getting old" as a valid reason for the intensity of your symptoms; be sure to talk to your doctor about any new symptoms and your concerns.**
Is testosterone therapy relevant to GBS recovery?	• **There is no specific link between testosterone and GBS recovery. An endocrinologist should assess the need for hormone therapy.**
How should a patient educate a new doctor about their history with GBS?	• **Patients should explain their medical history, residual symptoms, and baseline function to ensure accurate monitoring.** • **Remember: Doctors also learn from their patients!**
Does Miller Fisher Syndrome (a GBS variant) affect vision long-term?	• **Miller Fisher Syndrome affects the lens of the eye rather than the nerve of the eye. Therefore, it can cause temporary eye movement issues, but it does not directly lead to conditions like cataracts.**
Can neurogenic bladder issues improve over time?	• **A neurogenic bladder may improve, but in some cases, medications or surgical options might be necessary. Always consult your doctor.**

Final Takeaways!	**1.Do not assume new symptoms are “just residuals” - always check with your doctor.** **2.Stay as healthy as possible to maintain your nerve function and overall well-being.** **3.Engage with a multidisciplinary care team and support network.** **4.Advocate for quality-of-life improvements, including pain and fatigue management.**

Relevant Resources

Centers of Excellence: https://www.gbs-cidp.org/support/centers-of-excellence/

Doctor to Doctor Consult: https://www.gbs-cidp.org/doctor-to-doctor/

Find our Awardee’s Research Here: https://pubmed.ncbi.nlm.nih.gov/

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