Living Well with GBS/CIDP:

Slow and Steady: Life after GBS ~

Once the healing process has begun, we face a new challenge: pacing ourselves and using our energies wisely. For years, doctors have been cautioning patients to avoid pushing themselves to the point of fatigue. Many of us know how difficult it is, however, to resist the urge to dive into activities we've missed during the weeks and months following diagnosis.

The body will exact its price, as two of our members have found these past few months. Elaine Sparrow, whose GBS occurred in 1966, was continually cautioned by her doctors and says that curbing her physical activities was one of the hardest parts of recovery. Many GBS survivors can attest to the fact that when we overdo we often don't feel the consequences until the next day or even several days later. Our bodies talk to us and we need to listen. The human body is a wondrous machine that heals in its own time.

We're all familiar with the story of the tortoise and the hare. GBS is another example of how slow and steady wins the race. As Dr. Joel Steinberg of the Foundation might say, "Sit down before you fall down."

A hint: Remember when you were young and how good it felt to take a nap? We all need to give ourselves permission to take a nap. Naps are good at any age!

9/06

"Fellow sufferers of Neuropathy might want to try this ~ nothing ventured nothing gained"

"Six years ago the tingling in my toes was diagnosed as the early stages of Peripheral Neuropathy. My symptoms progressed to almost complete numbness above my ankles, causing discomfort and pain, especially at night. About a year ago I began applying Vicks VapoRub to my toes to kill a fungus under some toenails. Not only did it control the fungus, but I began to notice sensitivity in my feet again, where before I couldn't even feel the prick of a sharp pin. So I started applying the Vicks on the entire surface of both my feet. I again have feeling in both my feet and the numbness up my legs seems arrested. There is still some tingling and discomfort in my toes at night but it is so slight I no longer use Neurontin. My doctor is as amazed as I am and has encouraged me to keep with it. I apply Vicks Vaporub -- the odorless, greaseless cream in a tube -- to my feet and cover with socks every night before bed."

Someone from the western part of Colorado suggests checking out this website:

http://health.groups.yahoo.com/GBS_CIDP.

Summer'05

".... Diet soda is not a diet product. It is a chemically altered, multiple Sodium (salt) and Aspartame containing product that actually makes you crave carbohydrates. It is far more likely to make you gain weight.....

If you are using Aspartame (NutraSweet, Equal, Spoonful, etc.) and you suffer from spasms, shooting, pains, numbness in your legs, cramps, vertigo, dizziness, headaches, tinnitus, joint pain, unexplainable depression, anxiety attacks, slurred speech, blurred vision, memory loss, (and the list goes on), you may have Aspartame Poisoning. some people have been incorrectly

diagnosed with Fibromyalgia, MS, Lupus, etc. Their symptoms disappear when Aspartame is eliminated from the diet. "

This was part of a 10 page report that a Dr. friend sent to me that he wanted me to be aware of in light of my history with GBS. "Nerve damage is nerve damage and you need to make sure you stay away from Aspartame. You already experience some of these symptoms. Don't complicate what you already have by using Aspartame." My friend said in his note. I share this with you since we all need to be aware of the risks of "chemical food".

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1/05

"If GBS or CIDP has left you with lessened strength in your hands and arms, and you need to work in the kitchen, try stacking dishes you use the most on the lowest shelves and keep them in smaller stacks."

"Use Corelle dishware to further reduce weight"

"If your feet are hurting get yourself some 'SMART-WOOL' brand socks. (The company is from Steamboat.) They're soft against your skin, support your feet, and protect against rubbing from braces and shoes. Your feet will thank you and feel cuddled, loved, and comfy! Allergic to wool? Don't like that wool scratchy feeling? They have other fibers, but their wool is special=not scratchy at all."