

Polio Perspective

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DIETING and PPS: RED HERRINGS and LOW BLOOD SUGAR

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Q.

I have been having more weakness and fatigue so I went to an orthopedist. He said that I'm "too fat," that I should lose five or ten pounds to take weight off my legs and I would get stronger. I am at the ideal body weight for my height. Would losing ten pounds cure my weakness and fatigue?

A

WEIGHT LOSS is the red herring of PPS treatment, not the herring you eat but a herring doctors who know nothing about PPS try to feed you. Many polio survivors have been told that if they'd only lose weight their PPS symptoms would disappear. In her study of 125 polio survivors Margaret Campbell found that weight was not related to any PPS symptom. A four year study of US and Swedish polio survivors found that Americans were ten pounds heavier to begin with and gained eight pounds over the four years, compared to Swedes gaining one and one-half pounds. Still Americans had no greater loss in strength or increase in any PPS symptom as compared to the lighter Swedes. Sure, if you're 5 foot nothing and weight in at 250, you need to drop some pounds. But losing weight is not the cure for PPS. However eating well is a front-line treatment for PPS. We asked polio survivors to list what they usually ate for breakfast and rate their symptoms on our 1998 International Post-Polio Survey. We found that the typical post-polio breakfast consisted of coffee, a slice of toast--and sometimes cold cereal--which provided about 9 grams of protein. The polio survivors weighed 160 pounds on average which means that their bodies needed to take in 75 grams of protein each day --25 grams at each meal --to maintain that weight. So polio survivors in the study were

missing 16 grams of protein at breakfast. The more protein they were missing at breakfast the more fatigue, muscle weakness and pain they reported during the day and the more cups of caffeine-loaded coffee or tea they drank.

We then brought polio survivors into our laboratory. We measured blood sugar and attention and found that the lower the blood sugar, the worse polio survivors' did on attention tests. Attention was about 20% below normal even though their blood sugar was in the normal range. In fact, polio survivors' ability to pay attention was actually worse than in diabetics who had been given too much insulin! So, polio survivors' brains act as if they were hypoglycemic.

Why might this be true? There are receptors on the surface of the neurons that latch onto sugar molecules to pull them inside. These receptors are vital because blood sugar is neurons' only fuel. And here's where the problem likely lies. Sugar receptors are made of protein. Recent studies have found that protein factories inside neurons are breaking apart in polio survivors who have new muscle weakness. So polio survivors may not make enough protein to manufacture all the blood sugar receptors they need to take in the amounts of sugar required for neurons to function properly.

What should polio survivors do to treat their hidden hypoglycemia? They need to eat three to five times a day and have protein at every meal, especially at breakfast. We recommend that polio survivors eat immediately after they get up, since they need to break their fast and fill their tanks for the day ahead before stressing hungry neurons by bathing and dressing. (For some breakfast and snack ideas go to the POST-POLIO "DIET" article.) We aren't recommending an "all protein, no carbohydrate" diet --or a "diet" at all --but for polio survivors to take in the amount of protein their bodies need to function properly. Our patients do worry that eating protein, stopping exercise and resting more will cause them to gain weight. One patient proved the exact opposite. Abby, a programming whiz at AT&T, charted on his computer the number of grams of protein he ate and weighed himself once a week. We had given him braces, crutches, a scooter and told him to rest. He religiously ate protein at breakfast and for snacks, limited portion sizes and reduced fats. Abby lost 1 1/2 pounds each week. Other patients have had similar results, or their weight has not increased when they slowed down. (But please check with your doctor and have your cholesterol, thyroid and blood sugar measured before changing your eating habits and trying to lose weight.) Protein: It's what's for breakfast.

Just a reminder that exercise isn't the answer for polio survivors wanting to lose weight. Folks don't realize how many calories they burn by doing everyday things. Look how many calories those without polio burn during 20 minutes of activity: sleeping or watching TV (21); talking or writing (42); typing (54); dressing or washing (74); walking slowly (80); preparing a meal (92). Washing and dressing, walking around the house, answering e-mail, napping, making three meals, talking to a friend, balancing your checkbook and watching TV burns 500 calories each day—exactly the amount you must lose each day to drop one pound. If you want to lose weight cut your protein intake, talk to more people, send more e-mail and take a nap.

Medicare's Wheelchair and Scooter Benefit

If your doctor submits a written order stating that you have a medical need for a wheelchair or scooter for use in your home, Medicare will help cover any of the types listed below. Generally, Medicare will

pay 80% of the Medicare-approved amount, after you have met the Part B deductible. You pay 20% of the Medicare-approved amount. Wheelchairs (both manual and power) and scooters are also known as “mobility assistive equipment.”

Medicare will help cover your wheelchair and scooter, if you meet all of the following conditions:

- You have a health condition that causes difficulty moving around in your home.
- You’re unable to do activities of daily living (like bathing, dressing, getting in or out of a bed or chair, or using the bathroom) even with the help of a cane, crutch, or walker.
- You’re able to safely operate, and get on and off the wheelchair or scooter, or have someone with you who is always available to help you safely use the device.

Also, the equipment must be usable within your home (for example, it’s not too big for your home or blocked by things in its path).

Types of Mobility Assistive Equipment:

Manual Wheelchair

If you can’t use a cane or walker safely, you may qualify for a manual wheelchair. The manual wheelchair you choose can’t be a high strength, ultra-lightweight wheelchair that you could buy without renting first.

Rolling Chair/Geri-chair

If you need more support than a wheelchair can give, you may qualify for a rolling chair. These chairs have small wheels that are at least 5 inches in diameter. The rolling chair must be designed to meet your medical needs due to illness or other impairment.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Power-Operated Vehicle/Scooter

If you can’t use a cane or walker, or can’t operate a manual wheelchair, you may qualify for a power-operated scooter.

Power Wheelchair

If you can’t use a manual wheelchair in your home, or if you don’t qualify for a power-operated scooter because you aren’t strong enough to sit up or to work the scooter controls safely, you may qualify for a power wheelchair. Before you get either a power wheelchair or scooter, you must have a face-to-face exam by your doctor. The doctor will review your needs and help you decide if you can safely operate the device. If so, the doctor will submit a written order telling Medicare why you need the device and that you’re able to operate it. Remember, you must have a medical need for Medicare to cover a power wheelchair or scooter. Medicare won’t cover this equipment if it will be used mainly for leisure or recreational activities, or if it’s only needed to move around outside your home. Also, in some areas, you may need to get your power wheelchair or scooter from specific suppliers approved by Medicare. Visit www.medicare.gov/supplier or call 1-800-MEDICARE (1-800-633-4227) for more information. TTY users should call 1-877-486-2048.

Note:

If you don’t need a power wheelchair or scooter on a long-term basis, you may want to rent the equipment to lower your costs. Talk to your supplier to find out more about this option. Some wheelchairs must be rented first, even if you eventually plan to buy them.

Fraud

Most doctors, health care providers, suppliers, and private companies who work with Medicare are honest. However, there are a few who aren’t. For example, some suppliers of medical equipment try to cheat Medicare by offering expensive power wheelchairs and scooters to people who don’t qualify for these items. Also, some suppliers of medical equipment may call you without your permission, even

though “cold calling” isn’t allowed. Medicare is trying harder than ever to find and prevent fraud and abuse by working more closely with health care providers, strengthening oversight, and reviewing claims data.

How to Spot Fraud and Abuse

You can help Medicare stop fraud and abuse by watching for the following examples of possible Medicare fraud:

- Suppliers offer you a free wheelchair or scooter.
- Suppliers offer to waive your copayment.
- Someone bills Medicare for equipment you never got.
- Someone bills Medicare for home medical equipment after it has been returned.

What to Do if You Suspect Fraud and Abuse

If you suspect billing fraud, contact your health care provider to be sure the bill is correct. If your doctor, health care provider, or supplier doesn’t help you with your questions or concerns or if you can’t contact them, call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

For More Information

Medicare is here for you 24 hours a day, every day. To get more information, visit www.medicare.gov or call 1-800-MEDICARE. For more information about Medicare’s fraud and abuse activities, visit www.stopmedicarefraud.gov.

Too Much Fun

by Millie Malone Lill

Who knew there was such a thing as too much fun? I always knew housework would wear me out and so I cleverly avoided it whenever possible. But stuff that's fun is also exhausting? That is just not fair. I know, “whoever told you life was fair was a liar.” But still...

This morning as I write this, my fatigue level on a scale of 1-10 is about a 30. And it's all because of a fun weekend. On Friday, my grandson came over and helped me assemble a new desk. My old desk was not a computer desk and did not have the lowered keyboard tray, so I had to type with my elbows elevated. Not good. My shoulders were giving me fits. So I ordered this really nice computer desk from Staples. Assembly required, of course.

I had read all the reviews of this model before I ordered it and all of them advised assembling it where it will stay as it is extremely heavy once put together. Great. My computer is set up in my bedroom on the far side of my bed. That meant I had to remove everything in that area to clear the space for putting my new desk together. Out came the drawers of the old desk so it could be lifted over the bed and stashed in my living room. Then the printer stand, the printer itself, the computer and all its varied components. Finally the two big boxes of desk innards were torn apart, contents sorted, tools gathered up and we could get down to business.

One of the first things we discovered was that unless we wanted blistered palms from screwing the components together, we would have to locate an electric screwdriver. A quick trip to WalMart solved that one, although my grandson vetoed the cute pink one I chose. Fine. The red one was actually cheaper anyway. Back home and back to work.

Many hours later, the desk was mostly together. Somehow we did not have quite enough screws to put the hinges on the door to the CPU compartment. Working with Justin was fun and we laughed a lot, but getting up and down off the floor was not good for me. I took Justin home and, when he said he'd back to finish up the next day, I told him no. I knew I'd be doing the payback for that day's entertainment on the next day and probably for several after that. But I now have a desk with a keyboard tray that allows me to type with my arms resting on the arms of my chair.

Saturday morning, I woke up in agony. I knew this would happen but as usual I thought this time I'd get away with it. Ha. As if that ever happens. I had bought a ticket for that evening's performance of the Happiness Express Chorus, a barbershop type musical evening. I valiantly ignored the chaos of desk drawers on my dining room table, printer stand and printer in the living room, papers all over just so I could gather enough energy to attend the concert. Which I did and it was very enjoyable, too.

However, Sunday was the meeting in Omaha of Nebraska Polio Survivors Association and our speaker was to be a service dog trainer. I had already made arrangements for a couple of friends to go with me, so, even though by this time I felt like road kill, I made the trip. Of course, it was fun and informative and very very enjoyable, as I knew it would be. And going out to eat with my friends afterward was great.

Now it is Monday morning. There is a columnist, Robert Kirby, who writes for a Salt Lake City newspaper. His latest column mentioned PTFD. Not PTSD, Post Traumatic Stress Disorder, but PTFD, Post Traumatic FUN Disorder. That's what I have today. It's a terrible ailment, very prone to I-told-you-so scoldings on top of the roadkill feeling I already have. I'm afraid this PTFD thing is going to be chronic in my case as I not only don't learn from others' mistakes, I don't learn from my own either. No matter how many times I have lectured other polio survivors about overdoing and having to pay the consequences, I keep on subjecting myself to a flare up of PTFD.

So here I am, PTFD in full force and most of the stuff that should be neatly in place as part of my "office" is still in the living room. My old desk has no drawers in it because they are piled on the table and chairs. There are piles of yet-t-be-sorted papers everywhere. Does anyone want to come and help me clean up this mess? I promise it won't be too much fun.

Web Corner

Link between anxiety and chronic pain:

<http://www.medicaldaily.com/anxiety-and-chronic-pain-sufferers-share-biological-mechanism-could-lead-new-335426>

Self defense tips for wheelchair users:

<http://www.transfermaster.com/blog/view-post/Self-Defence-Tips-For-Wheelchair-Users>

Reversing Parkinson's Disease:

<http://www.iflscience.com/health-and-medicine/parkinsons-therapy-revived-after-20-years>

What Type A People Want You to Know:

<http://www.cnn.com/2015/05/27/health/type-a-personality/index.html>

Joni Mitchell Laughs at Fame in Newly Animated Eighties Interview

<http://www.rollingstone.com/music/videos/joni-mitchell-laughs-at-fame-in-newly-animated-eighties-interview-20150526>

Which Infectious Diseases Do We Fear Too Much and Which Too Little:

<http://blogs.jwatch.org/hiv-id-observations/index.php/which-infectious-diseases-do-we-fear-too-much-which-not-enough/2015/05/21/?query=pfw>

Elevated blood lipids are uncommon in patients with post-polio syndrome – a cross sectional study

<http://www.biomedcentral.com/1471-2377/15/67>

World's First Hoseless, Maxless Cpap:

<http://www.fundairing.com/journal/2015/4/30/introducing-the-worlds-first-hoseless-cordless-maskless-battery-powered-cpap-device>

Post Polio Conference Information:

<http://www.papolionetwork.org/pps-conference-corner.html>

Fibromyalgia now considered as a lifelong central nervous system disorder:

<http://www.news-medical.net/news/20150518/Fibromyalgia-now-considered-as-a-lifelong-central-nervous-system-disorder.aspx>

A Little Bit of Humor

THE PRICE OF BARBIES

One day a fella was driving home when he suddenly realized that it was his daughter's birthday and -- shock -- he hadn't bought her anything.

Out of the corner of his eye he notices a shopping mall. Knowing that it was 'now or never', he pulls his car through three lanes of traffic, finds a parking bay and runs into the mall.

After a frantic search he finds a toy store, goes inside and attracts the attention of the shop assistant. When asked what he'd like, he simply says: "a Barbie Doll".

The shop assistant looks at him in a condescending manner and asks, "So Sir, which Barbie would that be?"

The man looks surprised so the assistant continues, "We have 'Barbie Goes To the Ball' at \$19.99, 'Barbie goes Shopping' at \$19.99, 'Barbie goes Clubbing' at \$19.99, 'Barbie Goes To The Gym' at \$19.99, 'Cyber Barbie' at \$19.99, and 'Divorced Barbie' at \$249.99."

The man can't help himself and asks, "Why is 'Divorced Barbie' \$249.99 when all the other Barbies are selling for \$19.99?"

"Well, sir, that should be obvious!" says the assistant. "Divorced Barbie comes with Ken's house, Ken's car, Ken's furniture, ?"