

POLIO PERSPECTIVE
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Polio in Under Two Minutes

by Constance Habakangas

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"PPS In Under Two Minutes"

Have you tried to explain Post Polio Syndrome to a friend or relative? Maybe half-way through you notice them nodding off?

Try this two minute drill.

Our brain communicates with our muscles through the nerves. Polio destroys those nerve cells causing our muscles to die. The beautiful thing about nerves is that they help each other. When one goes down others help out, so a person can lose many nerve cells and not experience much dysfunction. Most Polio survivors have been living in this state of fewer nerve cells for years. If they were very young when they contracted Polio they may have grown up thinking this was normal. All people's nerve cells die off with age. For the normal person, having many nerve cells, this is not a problem. For those of us that have been living with a reduced number of nerve cells, this can result in a variety of symptoms including weakness, fatigue and pain, to name just a few.

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Some Examples:

Polio stuff or PPS stuff, or you know what I mean: Polio folks get up in the morning, too tired, moving slow, so have spaghetti for breakfast so they can take their medicine.

Polio folks have a "piano player mind" -- doesn't shut off when you need to rest the most -- sugar does shuts the body down, and revs the mind up.

Polio folks are often misunderstood. What comes out of the mouth is sometimes said faster (or slower) and does not keep up with the brain. We know what we want to say but have one heck of a time getting it out.

Polio folks have eyes that focus sometimes, and sometimes not. They can miss an entire chapter in the book they are reading, and hope they signed a contract right, if they could read it in the first place. Eyes twitching, usually indicates they are on circuit overload.

Polio folks, largely Type A's, are definitely driven beyond realization that they hit the Polio wall sometime back but didn't even notice. They say they will pace, will stop soon and lie down. Sometimes they do lie down, and then all of a sudden are up and at it again, not even thinking that they made a "deal" to go rest. The scrolling piano player mind again, wouldn't shut off long enough to allow them to rest in the first place.

PPS folks are successful people who drove themselves hard for those successes. Three times harder than the average "normal" person.

Polio folks are afraid of imposing on others, would rather do it themselves than dare to ask for any help.

Tote that barge, lift that bale, even in the laps in their wheelchairs. "No, i'm fine, i can do it" -- more Type A.

Polio folks can be starving, and then after eating, feel sick. Soft muscle, any soft muscle can be affected by PPS. Eating too fast may be a key.

Polio folks have heartburn, lots of us have hiatal hernias, Polio folks, or lots of them, have high blood pressure.

Polio folks often get the "oh, but you look like a million" -- it is downright impossible to explain this.

Polio folks often have allergies, you can tell by the kleenexess in the car, in the kitchen, by the bed, by the sofa, and the ones still sticking out of the nose.

Polio folks have itchy ears, hence the mad dash for a bobbie pin to help alleviate the wild itch – symptomatic nerve system?? So some PPS doctors say.

PPS folks have a thermostat problem, body temperature low, legs frozen to the ground, top half burning up and sweats -- menopause may be excluded here.

PPS folks have a real thing with sensitivity - cold or hot, or feelings hurt, emotions on high.

Polio folks sometimes have a startle reflex problem. You can tell this easily the next time they are startled from a piece of lint floating in the air, and they have landed in the arms or lap of a stranger. A PPSer may never have originally known anyone else with Polio, but when PPS hits it is critical for them to find a true peer group for support and to gather the knowledge that the ones that started with PPS earlier have already gathered, sorted through and found to be accurate and helpful.

~~ by Constance M Hanby Habakangas

A BLOOD TEST FOR POST-POLIO MUSCLE PAIN?

By Dr. Richard L. Bruno

*Chairperson International Post-Polio Task Force
and*

Director The Post-Polio Institute and International Centre for Polio Education

Q: Recently I had arm and chest pain. I went to the ER. The only abnormal blood tests showed high C-reactive protein and high creatine kinase. My blood pressure and cholesterol are normal, I have never smoked and I'm thin. My EKG showed that I hadn't had a heart attack. Could high CRP and high CK be related to PPS?

A. C-reactive protein is a blood marker for inflammation somewhere in the body. High CRP can be seen with type 2 diabetes, autoimmune diseases and cancers. Could inflammation somewhere in your body, as indicated by your elevated CRP, be related to PPS? Fifty consecutive patients evaluated at The Post-Polio Institute had CRP measured. The patients were on average 59 years old and 55% were women. Thirteen percent had an elevated CRP, 66% of whom were men. CRP was on average nearly three times the normal value. However, there was no significant difference between those with high and normal CRP on self-ratings of daily fatigue, difficulty with self-care or ability to perform activities inside or outside of the home. So, there is no evidence that elevated CRP or inflammation is related to PPS, either to post-polio fatigue or difficulty in functioning.

Recent studies have found that elevated CRP is related to having a heart attack or stroke. The theory is that a bacterial or viral infection (although definitely not a poliovirus infection) somehow inflames

arteries and causes them to clog. Our 1985 National Survey found no more heart disease or high blood pressure in polio survivors than in the general population. But two studies found that 5% more male post-polio patients had abnormally elevated cholesterol as compared to the general population. In one of the studies, only 33% of those with high cholesterol had been given a cholesterol screening test by their doctor and not even 25% were on cholesterol-lowering medications, like the statin drugs such as Lipitor, Pravachol and Zocor. This is not good, since reducing “bad” cholesterol reduces heart attack risk. and may increase survival even after having a first heart attack. But, as you know, statins can and do cause muscle pain and can cause muscle breakdown so several may need to be tried before finding one that helps (see CHOLESTEROL DRUG article in the POST-POLIO LIBRARY <http://www.PostPolioInfo.com> .

Statin drugs provide a connection between CRP and CK--in polio survivors. CK is an enzyme released when muscle is damaged. One half of one percent of anyone taking a statin develops muscle breakdown, which causes muscle pain (especially in the calves), muscle weakness and an increase in CK. Even without muscle breakdown or an elevated CK, some polio survivors report muscle pain or weakness when taking a statin, usually one of the older statins like Lipitor. And polio survivors can have an elevated CK without taking a statin. Two studies found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In our fifty Post-Polio Institute patients, 21% had abnormally elevated CK levels (on average about 33% higher than normal) with men also having higher CK than did women. But, as with CRP, there was no significant difference between those with high and normal CK on self-ratings of daily fatigue, difficulty with self-care or the ability to perform activities inside or outside of the home. However, an elevated CK may mean that polio survivors are making their muscles work too hard and are causing them to break down.

So, neither CRP nor CK is related to fatigue or loss of functional abilities in polio survivors. However, all polio survivors need to have their cholesterol and CRP measured to assess heart disease risk. And since an elevated CK indicates muscle breakdown, either from taking a statin or from muscle overuse, polio survivors should have CK measured before taking a statin. If you are worried about possible muscle weakness or breakdown with the statins, or the newer cholesterol-lowering drugs like Zetia and Vytorin, ask your doctor about using older medications like slow-acting niacin or bile acid sequestrants. Besides medication, polio survivors need to eat high fiber foods, reduce saturated fat, treat high blood pressure and stop smoking to keep their tickers ticking.

Prejudice

by Millie Malone Lill

There was a very interesting post on the internet this morning. A white person asked a black friend of his about prejudice. The subject was actually about white privilege and how if you are white you may not even realize that you have an advantage over our black or brown brethren. There are certain things you never have to face.

As I read this article, I was thinking that a few of those problems pertained to disabled people, too. I know that as a white person, I won't have all the problems that people of color face, but I do know a bit about prejudice myself.

I know because I am:

1. a woman
2. a disabled woman
3. an overweight disabled

woman

4. an old, overweight, disabled woman.
5. An old, overweight, disabled woman in a power chair

In some people's eyes, this makes me "less than." I hear people say things like "people like you" without knowing what I'm like in fact. They decide, without even knowing my name, that I am on welfare because I'm lazy, that I'm using my disability to milk the system, that I have a mental problem, and that I am probably faking needing the chair because they have seen me walk.

I've lived in this apartment for six years now. The going was pretty rough for the first three years, with people constantly telling me I was not welcome here because I couldn't walk, that I need to come and go through the garage door rather than the front entry, that I cheated at getting my apartment because I walked in, then sneaked my wheelchair in with no one knowing I sometimes use one. There was a big meeting of all the members of this Cooperative wherein our managing agent and our Resident Service Director explained the Fair Housing Act, under which this building falls, and the non-discriminatory papers each of us signed on buying our cooperative shares. There was also an explanation of what independent senior housing means. It means that Realife, my Coop, does not provide any services other than maintenance. If I need a personal assistant, I can hire one on my own. If I need help with meds or meals or laundry or cleaning, I can hire it done at my own expense. I thought this was understood.

Fast forward to a couple of weeks ago, and I had to go through it all again. By now, most of the other residents have realized that I'm a decent person, that I did not buy a power chair with the express purpose of ruining all the carpets in the building. Oh, yes, I was actually accused of that! There still remains one person who confronted me in the office of our Resident Service Director. She was outraged, still, after six years, that there had been no opportunity to vote against my living here. No matter how many times she has been told that there was no legal way to vote against my living here, she doesn't want to hear it. She got so angry she slapped the arm of my chair.

After I lodged a formal complaint against her, and after she was told that one more such action and she could go to jail, she has now simmered down. I think the situation is now under control. She did apologize, but even while she was in the act of apologizing, she kept insisting that I move to the low

income housing across the way. I explained that since I own a farm, I do not qualify for low income housing. I think she believes that I live here free, since she kept going on about how her maintenance fee is paying for the damage my chair does to the carpets. My own maintenance fee helps with that, too.

You see, there it is. I'm disabled, so I must be in poverty. I can walk, so I don't need the chair. She has jumped to one conclusion after another, based purely on her perception of a disabled person. She sees only what her preconceived notion allows her to see.

I am not fishing for sympathy here. I have never wanted pity or sympathy. Empathy. That's what I want. None of us has an iron clad guarantee that they won't end up in a wheelchair or even become bedfast. Not everyone has to like me. I only want people to get to know me so that if they dislike me, they do so for a reason based on actual fact, not on a preconceived notion of who they think I am.

Web Corner

Statin Side Effects: Weigh the benefits and risks

http://www.mayoclinic.org/statin-side-effects/art-20046013/?utm_source=newsletter&utm_medium=email&utm_campaign=heart-healthy **Like Comment**

Boy with polio an inspiration to others more fortunate

<http://news.thaivisa.com/thailand/boy-with-polio-an-inspiration-to-others-more-fortunate/143193/>

Good Talks Needed to Combat HPV Vaccine Myth

<http://www.personalmedicare.com/good-talks-needed-to-combat-hpv-vaccine-myth/>

Famous Polio Survivors

https://www.facebook.com/permalink.php?story_fbid=998654493547271&id=440616396017753

Utah's National Parks for Wheelers and Slow Walkers

<http://barrierfreeutah.com/>

What Would You Do? Video

<https://www.facebook.com/wwyd/videos/10153687254270899/>

Books about the polio experience

<http://www.post-polio.org/edu/aboutpol/books.html>

Nutrition Myths Debunked

https://www.washingtonpost.com/lifestyle/wellness/healthy-sweeteners-protein-powerhouse-quinoa-and-other-nutrition-myths-debunked/2016/08/24/2391bbd6-6944-11e6-8225-fbb8a6fc65bc_story.html?wpisrc=nl_sb_smartbrief

Grow Young Fitness for Seniors

https://www.washingtonpost.com/lifestyle/wellness/healthy-sweeteners-protein-powerhouse-quinoa-and-other-nutrition-myths-debunked/2016/08/24/2391bbd6-6944-11e6-8225-fbb8a6fc65bc_story.html?wpisrc=nl_sb_smartbrief

The Man Who Eliminated Smallpox Dies

<http://www.theatlantic.com/news/archive/2016/08/remembering-da-henderson/496820>

Other Polio Newsletters

Boca Raton

www.postpolio.wordpress.com

Pennsylvania Polio Survivors Network

www.postpolio.wordpress.com

Polio Survivors Network (UK)

<http://www.poliosurvivorsnetwork.org.uk/>

A Little Bit of Humor

One day God was looking down at Earth and saw all of the rascally behavior that was going on. So he called one of His angels and sent the angel to Earth for a time.

When he returned, he told God, "Yes, it is bad on Earth; 95% are misbehaving and only 5% are not."

God thought for a moment and said, "Maybe I had better send down a second angel to get another opinion." So God called another angel and sent him to Earth for a time.

When the angel returned he went to God and said, "Yes, it's true. The Earth is in decline; 95% are misbehaving, but 5% are being good."

God was not pleased. So He decided to e-mail the 5% that were good, because he wanted to encourage them, and give them a little something to help them keep going.

Do you know what the e-mail said? Okay, I was just wondering, because I didn't get the email either.