

Polio perspective

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PPS in under two minutes by CONSTANCE INGRAM c 1992

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 kleenex-es 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.

Skinless Days by **Millie Malone Lill**

There are days when things overwhelm me. When everything hurts except what doesn't work and that hurts, too. I call these days Skinless Days. It's as if my skin has been removed and all my nerve endings are exposed. The barest, lightest touch hurts. Anything anyone says to me is going to make me over react. On these days, I cry at dog food commercials, I'm so emotional.

Some days I can handle the slings and arrows that life throws at me with wit and grace. Well, with what passes for grace with this lumpy old body of mine. But there are those days when someone says something so mean spirited to me, so unexpectedly, that it takes a layer of my protective covering off. If I get several of those comments within a short period of time, I become skinless.

Mind you, my life is pretty good. I have a large and loving family and a group of friends I can always count on. They are the people I turn to when my skin is gone. Sometimes, even those loving people will say something or do something that hurts. They don't intend it to hurt, but when you have no skin, everything hurts, every slight touch can send you into tears.

Polio survivors are probably among the toughest people on the planet. We live with pain every day. For some of us, just our daily activities are all we can handle and some of us can't even do those minimalistic things. But we cope. We 'do it anyway,' even when we know we shouldn't. We mop the kitchen floor with our backs in spasm because we don't want to go to bed in a dirty house. We say "No...kay" when we should just say NO.

Then comes an event or a series of events that peel the hide right off of us. On a day when someone here has told me, for the second time, that twenty years ago people who could not walk were not allowed to live here, implying that I should leave, followed by another person complaining because my dog woofed when they stood outside my apartment door talking, followed by a complete idiot telling me "You look so good! Are you sure you need that wheelchair?" I am down to Skinless. Then another person says, "I wish you wouldn't always remove a chair from the table so that you can sit up there with your chair. Can't you just sort of squeeze onto the corner and leave the chairs alone?" and I lose it.

Taken individually, none of these complaints should be a big deal. I can tell the first person that this is not twenty years ago and that it is now illegal to discriminate against me because of my inability to walk. I could explain to the talkers that Fiona thinks someone is coming into the apartment when she hears voices outside our door. I could tell the person who says I look too good to use a wheel chair that he looks good, too, and ask if he really needs the use of his legs. A withering look would likely silence the woman who does not want me to sit up to the table with the 'real' people. Or, I could ignore them all and just go about my life as I usually do.

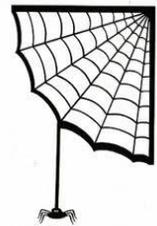
However, when all of this hits the fan at the same time or in a relatively short space of time, it lays me low. I am tempted to hide in my apartment. I try to think of ways to mollify the bullies, because that is what they are...bullies. It amazes me that people in their 8th decade of life still want to bully others. I would have thought that they'd know better by then, would have developed some compassion. I would be wrong. Oh, not all old people are intolerant grouches. I live among some of the nicest people in town. But four or five people here have made life very difficult, not just for me, but for anyone they think does not fit in. One woman has been so traumatized by these elderly curmudgeons that she has not left her apartment in the three years I've lived here and I don't know how long before that.

I avoided these few bullies for awhile, and eventually my skin grew back. I did stand up to them. I remembered telling my children that they were never to start a fight, but it would be OK to finish one, to never back down from a bully but to stand up to them. I was not advocating fighting, just letting my sons know that they had rights and it was OK to insist that these rights be respected.

I explained to the man who thought I should move out because I was unable to walk that this building comes under the Fair Housing Act and that it would be illegal for anyone to try to force me out because they don't like what my power chair does to the carpets. In fact, I told him, if I were a litigious sort, I could sue him for voting against me when I moved in here because his reason was that I was unable to walk. This is a cooperative and all new members must be approved by the board of directors. He has since not said a word about this subject.

The woman who didn't want me to sit close to the table because it meant moving a chair? I just calmly move the chair off to the side, out of the way, and smile at her pleasantly whenever I see her. She has not mentioned this again. In fact, I noticed at our last gathering that another woman, who normally parks her walker (the kind with a seat on it) actually moved out a chair and sat on the walker seat. Much safer than having to maneuver her 90+ year old body from walker to chair.

My little dog is handling the discrimination in her own way. She wags her tail at everyone she sees, whines till they pet her and gives their hands kisses. Granted, a lot of people would prefer she keep her tongue in her mouth, but even those can see she is trying to make nice. It's all just a matter of trying to keep my skin on and remembering that the bullies might also be having a Skinless Day.



The Web Corner

Some interesting sites for you to explore

A site where you can look up polio doctors in your area:

<http://www.post-polio.org/net/pdirhm.html>

Myra Goldick's Radio Network:

[Never Say Impossible – WQ4D Radio — Inspiring Friends Network](#)

A letter that we can download, print, sign and send to our congress people and senate people. We have a voice!

<http://www.post-polio.org/werestillhere/wsh2012a.pdf>

A presentation given to the Arizona Medical School by Micki Minner

Webcast.AHSC - Arizona Health Sciences Center Video & Podcasts
streaming.biocom.arizona.edu

Once again, I will post the link to the Post Polio Resource page

<http://www.i-sites.net/ppsrl/reslist.html>

Free diet plans online:

Free Diet Plans at SparkPeople

Some of us find we are having changes in our voices:

"What Your voice is Saying about You: Voice Changes and the Late Effects of Polio"
6:16am Sep from Post-Polio Health newsletter...
15 <http://post-polio.org/edu/pphnews/PPH26-2sp10p1-11.pdf>
post-polio.org

A little bit of humor

Little Susie

Little Susie, a six year old , complained: "Mother, I've got a stomach ache."

"That's because our stomach is empty", the mother replied. "You would feel better if you had something in it."

That afternoon her daddy came complaining that he had a severe headache all day.

Susie perked up: " That's because it's empty", she said. "You'd feel better if you had something in it."

Making Dinner

A true story:

My friend took his granddaughter, Ellie, to the park and, since there were no other children there, he played a game with her.

The game they played was "Making Dinner," which involved creating lots of "dishes" made of mud. After all the preparation, the grandpa asked, "Can I eat now?"

Little Ellie replied, "No, Grandpa, this is pretend."