

POLIO PERSPECTIVE

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Is Heat Intolerance Also a Post-polio Problem?

by Richard Bruno PhD This article is from the Polio Post News North Central Florida Post-Polio Support Group Sept 03 Question:

I read about 'cold intolerance', that Polio Survivors are always cold. My feet are always cold in the winter, but I have the most trouble in summer. I get exhausted in the heat, especially when it's humid. Is heat intolerance also a post-polio problem?

Dr Bruno's Answer:

You bet. In our 1985 National Post-Polio Survey cold caused muscle weakness in 62% of polio survivors, muscle pain in 60% and fatigue in 39%. But that survey also found that **39% of Polio**

Survivors have fatigue when it's hot.

Whether it is cold or hot, polio survivors have three strikes against them when it comes to controlling their body temperatures. First, the poliovirus damaged the hypothalamus, the part of the brain that serves as the body's thermostat. Second, the polio virus killed neurons in the spinal cord that make the veins in your skin become smaller or larger as the temperature changes.

Basically, polio survivors' veins are always too big. When it's cold outside warm blood pools in those big veins near the surface of the skin, causing heat in the blood to radiate into the air, the skin to get very cold and to look purple or even blue. When it's hot outside, or when polio survivors take a long hot bath or shower, the skin becomes lobster red as the veins and the arteries open wide and hot blood rushes to the skin.

When polio survivors stand up, gravity pulls blood into the open veins in their legs and **blood pressure can drop**, causing fatigue, light headedness or even a faint. And then there's the third strike: Polio survivors who have smaller leg muscles due to polio damage causing muscle atrophy, have more blood pooling in the lower legs, since muscle contraction is needed to help to pump blood back toward the heart.

So, since your body now can't regulate its own temperature, you will have to do it. Our 1983 study found that polio survivors' nerves function as if it is 20 degrees colder than the temperature of their skin. So in winter, polio survivors should dress as if it is 20 degrees colder than the outside temperature. You need to dress in layers so that you can regulate your body temperature by changing the amount of insulating clothing covering your body.

But the trick is to stay warm from the word go. You should dress straight after showering when your skin is warm and red. Try wearing heat-retaining socks or even long-johns. (If you ever need surgery remember to remind the doctors and nurses that you get cold easily so they can provide a heated blanket in the recovery room.)

When it is hot, stay out of the sun, move more slowly and take more **frequent rest breaks with your feet elevated** to make it easier for blood to flow back to your heart so that you can **prevent foot swelling** and keep your blood pressure up. It's especially important to have smaller amounts of food for lunch, have cool foods and cold drinks, and to take a feet-up break after eating, since midday is when polio survivors have the most trouble with dropping blood pressure and fatigue

It's also a good idea to take **cooler baths or showers in summer** and to keep the air conditioning turned up. Cool the car down too before getting in during the summer. But be careful. Whether you're being chilled by winter winds or by air-conditioning in summer, always cover your upper body, especially your neck, to prevent muscle spasms and headaches caused by cold air blowing on your muscles.

Many polio survivors don't realise that they can have as many symptoms and sometimes even more, during the change of seasons, when the thermometer goes up and down from day to night and from day to day. **Autumn and spring bring increases in symptoms**, especially muscle pain and headaches, as polio survivors' temperature-challenged bodies can't decide if they should sweat to stay cool or shiver to stay warm. Layering of clothing is especially important in a thermally-confused world for the bodies of polio survivors, unable to adapt to the temperature.

Tessa's Comments:

With summer approaching, excessive sweating in the heat can lower our potassium levels making it more difficult to cope with the heat of summer. **Heat drains us of energy when potassium is low** and palpitations and heart problems can occur. Low potassium also increases muscle weakness and swelling. **As you need a doctor's prescription to get Slow K now**, an alternative is boiling potato skins and drinking the water (make it into soup) to get more potassium. (Never throw your vegetable water away – full of minerals.) Other good food sources include most nuts, sunflower seeds, carrots, apricots, avocados and of course bananas.

Polio Biology of Fatigue, is there New Hope?

By Edward P. "Eddie" Bollenbach, MA

Professor Emeritus in Microbiology and Chemistry

Those of us who suffer the affects of the Post-Polio Syndrome know about fatigue. We often experience overwhelming fatigue, especially in particular muscles affected by polio. When a physician performs manual muscle tests on PPS patients they often seem puzzled because they expect to detect weakness. But if the patient gives a good effort at contracting muscle against resistance, using all their available muscle fibers, typically the clinician observes good strength in the muscle. For a normal person this effort would use only a fraction of available muscle fibers for this short test. So a physician may be confused because most or all of the available fibers contract completely in PPS as well as in normals. Each viable muscle fiber contracts or doesn't but when it contracts it contracts completely. If there are enough fibers there will be good instant strength against the resistance. But if one continues to contract the same fibers without a reserve of extra fibers to allow for rest, the dearth of fibers will fatigue along with incompletely innervated fibers present in PPS.

So fatigue is a proximate cause of PPS symptoms, and whether a person can produce a good instant power against resistance isn't an indicator of this. As a matter of fact polio damaged muscles with too few fibers will not be strong or even able to produce normal instant strength if enough fibers are missing even though the individual does not have symptomatic PPS. But in PPS something happens, probably at the synapses, and fatigue generation in muscle fibers is enhanced because of biochemical changes that occur inside the muscle.

Damaged motor nerves cannot transmit signals back to the brain. They propagate electrochemical signals to the muscles and the signals always move away from the brain. So pain and feelings of fatigue are not the result of neuron damage directly, but of muscle fiber insufficiency to maintain contraction over time. If localized muscle fatigue is a proximate event in symptomatic PPS the problems of PPS patients then are often the secondary symptoms which derive from muscle fatigue. Symptoms such as pain, generalized fatigue, muscle spasms, and exhaustion can result from faulty biochemical signaling

of depleted or partially innervated myofibrils in muscle.

PPS fatigue is the result of muscle fibers that are overworked to the point of exhaustion because there aren't enough properly functioning fibers to carry the load. In athletes that overdo training a similar situation arises. They have enough myofibrils but the load is so high in their work during training that their muscle fibers undergo a similar fate to that in PPS muscle fibers. In their case, though, it is the overabundance of work that precipitates the muscle changes in normal numbers of healthy fibers that leads to fatigue. If the athlete really over uses and over trains there will need to be a period of prolonged rest to get the muscle fibers back to their homeostatic condition with all the components, chemical and physical, back in balance. Rest relieves PPS muscle fatigue and general fatigue and also over training fatigue in athletes.

Although in PPS the same biology inside the muscle causes fatigue as in athletes, and the fatigue is relieved in the same way with rest, the load of normal daily tasks would not be excessive if enough undamaged fibers were present. But with PPS there often aren't enough healthy muscle fibers for many to carry out the activities of daily living. Nevertheless, since there are so few fibers to do the job they are working with the same over intensity and invoke the changes that occur in over trained athletes.

A recent paper has both shed light on the biological changes that occur within muscle cells during the process of fatigue and points directly to a drug class that may halt the changes that result in fatigue in muscle cells. Dr. Andrew Marks, a research scientist at the Columbia University College of Physicians and Surgeons in New York, and chair of the Department of Cellular Physiology and Biophysics, published a recent paper in the Proceedings of the National Academy of Sciences which sheds light on what happens inside a muscle fiber during fatigue and how it may be ameliorated and treated. [1]

Mark's research interests brought him to cardiology early in his career, specifically toward working out the questions involved in how heart muscle fatigues and leads to heart failure. Marks focused on the process of calcium moving inside heart muscle cells and how this calcium transport back and forth within cardiac muscle cells results in fatigue and disease in some patients. When this happens in the heart, smooth muscle builds up inside arteries of the heart, narrowing them and remodeling the heart which causes heart disease. As a result of this work Marks was instrumental in producing the first drug eluting stents that could be inserted into the coronary arteries to widen them and allow for increased blood flow. These stents are used routinely today.

His research interest in heart muscle led Marks to study how muscle contracts at the biochemical level and how continuing contraction (as hearts must do) results in fatigue. Here I will try to simplify the technical concepts that Marks began to understand and which led to his ideas about muscle fatigue, and what followed: ways to improve the process. There is an abundance of calcium inside muscle cells, both cardiac muscle and voluntary skeletal muscle. Before contraction this calcium is released from one part of the muscle fiber and is transported via a channel (a calcium channel) to a receptor which triggers muscle contraction. Marks was able to manufacture, in the laboratory, the receptor that calcium triggered to induce muscle contraction so he could study the process more intensely in the lab. He actually cloned and collected the calcium receptor.[2]

When a muscle contracts a protein called calstabin binds to this calcium receptor. Marks found that a faulty biochemical reaction resulted in poor binding of calstabin to the calcium receptor and worsened heart failure by reducing the capacity of the muscle to resist fatigue.[3] Prior to the year 2000 most muscle researchers felt fatigue was a result of lactic acid accumulating in muscle. However, there were problems with this explanation not the least of which was that lactic acid dissipates very quickly in muscle and the model didn't lead to any understanding of how lactic acid induced fatigue. Since then, because of Marks' and others, attention has turned to the faulty movement of calcium in cells as the genesis of muscle fatigue.

In the failing heart, it has been shown that when calcium doesn't bind to the receptor the way it should this causes some calcium to leak from its channel lessening the supply of calcium to properly contract muscle. The result is fatigue and eventually exhaustion. Marks entertained the idea that skeletal muscle fatigue may be caused by a similar mechanism and he used mice, swimming one group to exhaustion while another control group of mice rested. After muscle biopsies on the overworked mice he found the same leaky calcium channels he found in heart muscle failure. Subsequently Marks showed in human over trained cyclists the same changes, leaky calcium channels, that required days of rest to recover, and it occurred in their muscles exactly as it did in the exercised mice. Marks and his team went on to develop a drug which caused calstabin to bind more tightly to the calcium channels. When the drug was given to mice it was observed that the mice could run 10% to 20% longer on a treadmill than control mice postponing fatigue. The first group to react to this news was athletes and trainers hoping to use the drug to improve athletic performance. They think they've found a new way to use drugging without anabolic steroids to improve athletic performance.

The first thing I thought of was all of us with PPS. A 10% to 20% improvement in muscle endurance could take us from exhaustion to comfort. And maybe, just maybe, new drugs of a similar type could do even better in the near future.

HELP is Not A Four-Letter Word

by Millie Malone Lill

Yes, that word does have four letters, and yes, I know it's very hard for a polio survivor's tongue to wrap itself around that particular word, but it really isn't a naughty word. It's OK to use it. Sparingly, of course.

Any of you who follow me on Facebook know that I am in the process of moving from a one bedroom apartment on the second floor of Realife Cooperative to a two bedroom apartment on the ground floor. I tried doing it by myself, which did not work well, as anyone with a working brain could have predicted.

I always knew I was somewhat of a packrat, but I was a bit surprised to find that I am the Empress of the Packrat Clan. I pulled out stuff I had forgotten I even owned. In fact, by the end of the first week, I was beginning to suspect that another packrat, a disloyal subject, if you like, had been storing their bounty with me. Where on earth did all of this stuff come from?

After one particularly long hard day, I took more Flexoril than my sissypants system could handle. I awoke the next morning with a pain med hangover. Ringing ears, headache, slurry speech, blurry vision, all of the symptoms of The Morning After. Except the Night Before was no fun at all. I can't believe people actually go out and pay good money to feel like this!

That settled it. I called in the troops. I have a large extended family and while the numbers are dwindling due to the grandkids' urges to have lives of their own, I can usually rally a few muscles on my behalf. Everyone I asked came and emptied the upstairs apartment completely.

Now I'm sitting amongst boxes and bags of stuff to sort out and put away. My granddaughter, grandson, and friend even helped with that. Everything is still waiting to be unpacked, but the office stuff is in my guest room/office, my clothes are in my bedroom, kitchen stuff in the kitchen, and so on.

I think this place will soon be liveable, if not exactly tidy.

I discovered that I could work for about half an hour before my hips and back threw in the towel. So I'd sit for awhile, maybe do a little computer work, then hit it again. It works pretty well, as long as I stay down for about twice as long as I work.

I'm putting out an APB to find the scuzzy pack rat who dumped all their stuff in my apartment, so if you see a suspicious packrat, walking along, hands in his pockets, whistling softly as he peers around, grab him and make him come get his hoard. Thanks. You will be rewarded, if not in this life, perhaps in the next.

Web Corner

2nd European Polio Conference presentations

<http://www.informed-scientist.org/congress/2nd-european-polio-conference>

Post-polio information

<http://ohiopolionetwork.org/id70.html>

Accident Victim Regains Sense of Touch

<http://www.transfermaster.com/blog/view-post/Paralyzed-Accident-Victim-Gains-Back-Sense-of-Touch-Thanks-to-Brain-Implant>

Books and information on post polio

<http://www.postpolioinfo.com/>

The Psychology of Polio as a Prelude to PPS

<http://www.giorgionicoli.com.br/institutogn/P4.pdf>

Off the Beaten Path, adventures for the disabled

<http://us7.campaign-archive1.com/?u=17f310847c9388aef9061d2ec&id=2ef514b5f6&e=ccb4c74778>

A Healthy Dose of Compassion

<https://www.facebook.com/BALANCEDWAYofLIVING/posts/1293008450771017>

A request from your chronically ill friend

<http://www.upworthy.com/a-request-from-your-chronically-ill-friend-what-i-need-when-we-talk-about-my-sickness?c=upw1&u=98ff620d828644636bf152f00ec8df4e03cb9bf1>

Imagine the Possibilities

<http://www.transfermaster.com/blog/view-post/Why-do-Fallacious-Stereotypes-about-Disabled-People-still-continue-to-hold-back-so-many-Em>

Teen Writer gives her book to the Pope

<http://www.transfermaster.com/blog/view-post/Teen-Writer-Gives-Her-Book-to-the-Pope-2>

Other PPS Newsletters

Pennsylvania Polio Survivor's Network

<http://www.papolionetwork.org/>

Polio Australia

<https://www.polioaustralia.org.au/>

Polio Survivor's Network (UK)

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

Poli 'O Canada

https://www.marchofdimes.ca/EN/programs/PolioCanada/Documents/polio_spring_2003_newsletter.pdf

Atlanta Post Polio Association

http://www.atlantapostpolio.com/APPA_News-2016-spring-final.pdf

A LITTLE BIT OF HUMOR

A couple were in a busy shopping center just before Christmas. The wife suddenly noticed that her husband was missing and as they had a lot to do, so she called him on the mobile.

The wife said " Where are you, you know we have lots to do."

He said "You remember the jewelers we went into about 10 years ago, and you fell in love with that diamond necklace? I could not afford it at the time and I said that one day I would get it for you?"

Little tears started to flow down her cheek and she got all choked up... "Yes, I do remember that shop." she replied.

"Well I am in the gun shop next door to that."