



## **PPS QUESTIONS AND ANSWERS, MARCH, 1995**

**by Drs Richard Bruno and Nancy Frick**

**Compiled by Tom Walter**

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### **PLEASE NOTE: READ ME FIRST!**

These general answers and our on-line discussion on 3/7/95 represent what is written in the medical literature on PPS, our newest research and how we treat patients at the Kessler Post-Polio Service. They are NOT intended as therapeutic recommendations for you personally nor as a substitute for your being evaluated by your own personal doctor and a doctor who knows about PPS.

Every polio survivor (PS) is different and prescribed treatments must take those differences into account.

Post-Polio Sequelae (PPS) is a diagnosis of exclusion, meaning a physician must evaluate you and determine that no other condition is causing your symptoms. You may have PPS alone, PPS and another problem or a condition not related to polio at all. There are no medical tests that can prove you have PPS.

Read these answers, read the journal articles listed with each, and understand them fully. Take them to your doctor or therapist and ask them to read and understand them fully. Do not apply therapeutic techniques described here (especially exercise) on your own.

We very much hope these answers serve an educational purpose and that you integrate them with your own experience, personal wisdom and doctors' recommendations so that you can thrive, not just survive, with PPS!

Best wishes, Drs. Richard Bruno and Nancy Frick

### **ABOUT PPS PREVENTION & PROGRESSION**

There are no long-term studies of whether Polio Survivors (PS) who have no symptoms will develop PPS. Every time a study of PS is done, the percentage with new problems increases. The percentage was 22.4% in the first Mayo clinic study in 1982 and increased to 78% in a British polio hospital follow-up in 1987. At the NY Academy of Sciences Symposium on PPS April, 1994, the Mayo group and others thought that more than 90% of PS would develop some problems related to their polio.

Every PS is different. But, the rules that apply to every mortal apply to PS. Anyone who has too few

overworked, damaged nerves compensating for muscle weakness for over 40 years is bound to have some problems. And, when you add PS super Type A lifestyles and the fact they work more hours of overtime than non-disabled people, something's got to give.

But, the good news is that the study cited below and our new follow-up study of all the patients we have treated show that if you listen to your body and stop doing the things that cause weakness, fatigue and pain, PPS often plateau and can even decrease (see below: Exercise & Activity). One example: 18 months after their evaluation with us, PS who completed therapy reported 22% LESS fatigue; however, PS who refused treatment or dropped out of therapy early had 21% MORE fatigue at 18 months.

## References

Peach PE, Olejnik S *Effect of treatment and non-compliance on Post-Polio Sequelae*. ORTHOPEDICS, 1991, 14(11) : 1199. [[Lincolnshire Library Full Text](#)]

## ABOUT EXERCISE & ACTIVITY

Exercise has been the most hotly debated area in PPS. The studies cited below say three things:

1. Listen to your body! If you are doing things that cause fatigue, weakness or pain STOP DOING THEM!!! PS need to pace their activities, that is work and then rest about 2 times the amount they worked. Jim Agre showed that PS can do 240% more work if they PACE. You don't drive your car until it's out of gas; you shouldn't drive yourself to exhaustion, weakness or pain;
2. We only prescribe the non-fatiguing exercises devised by Rubin Feldman that have been shown not to hurt PS. But, these exercises are not given to all patients and are only prescribed after PS learn to pace and conserve energy! Patients are usually given gentle exercise after they get a new brace to keep muscle tone. The key word is NON-FATIGUING;
3. We have seen a small handful of PS who became deconditioned after surgery or illness. Pacing and resting doesn't mean sitting or sleeping all day and not moving. You should be doing what you need to do for yourself, and at your job, but in a paced, energy conserving, Type B fashion.

In our follow-up of all the patients we have treated, the three factors that were related to a significant decrease in fatigue were

1. completing the PPS therapy program;
2. doing absolutely nothing for 15 minutes twice a day;
3. using a wheelchair or scooter for distances.

## References

Young GR. *Energy conservation, occupational therapy and the treatment of Post-Polio Sequelae*. ORTHOPEDICS, 1991, 14(11): 1233. [[Lincolnshire Library Full Text](#)]

Feldman RM, Soskolne CL. *The use of non-fatiguing strengthening exercises in Post-Polio Syndrome*. In LS Halstead and DO Wiechers (Eds) *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Birth Defects Foundation, 1987. [[PubMed Abstract](#)]

Fillyaw MJ, et al. *The effects of long-term non-fatiguing resistance exercise in subjects with Post-Polio Syndrome*. ORTHOPEDICS, 1991, 14(11): 1253. [[PubMed Abstract](#)]

Agre JC and Rodriguez AA. *Neuromuscular function in polio survivors*. ORTHOPEDICS, 1991, 14(12): 1343. [[PubMed Abstract](#)]

## ABOUT FEET & LEGS

PS are notorious for having cold and purple "polio feet," caused in part by the smooth muscle around the veins being partially paralysed by the original polio. Without muscle to control their size, veins fill with blood and cause your feet to appear purple. Your feet become cold because the heat in this pooled blood escapes into the air. Back in 1983, we found that PS's nerves and veins act as if it's 20 degrees colder than the air, making it hard for the nerves, muscles and connective tissues to work. PS lost 75% of their muscle strength when the room temperature dropped from 85 to 65 degrees Fahrenheit.

Cold is the #2 cause of muscle weakness in PS but is the easiest to treat. We suggest that our patients take a bath in the morning, dry off and put on Polypropylene socks or long johns while they are still warm. Polypropylene (trade name: Gortex, Thinsulate) is a silk-like plastic that holds heat in but allows sweating.

Also, engorged veins can cause swelling, especially when feet get hot in Summer or after a long bath. Jobst compression stockings sometimes help, as well as keeping your feet up a lot during the day. But, leg swelling must be evaluated by your doctor!

### References

Bruno RL, Johnson JC, Berman WS. *Vasomotor abnormalities as Post-Polio Sequelae*. ORTHOPEDICS, 1985, 8 (7): 865-869. [[PubMed Abstract](#)]

## ABOUT GETTING OTHER DISEASES

PS can get all the diseases everyone else gets. That's why your doctor has to exclude all other causes for your new symptoms before you settle on PPS. In our 1985 National Post-Polio Survey we discovered that PS were on average more Type A - pressured, time-conscious, overachieving, perfectionistic than any other group of Americans, including those who already had had heart attacks. However, PS were no more likely to have heart attacks or high blood pressure than anyone else.

We found that PS also had 3 to 6 times more trouble with gut problems diarrhoea, constipation, ulcer and colitis - as compared to the general population. PS also have more headaches (but not migraines) and muscle pain (often called Fibromyalgia). And, there is also one study that suggests that more PS have hypothyroidism.

Also, 66% of PS report frequent anxiety and 31% of those who see us for evaluation have a Major Depressive Episode - that's 6 times the rate for the general population. Both old and new types of antidepressants are effective if prescribed for PS. Again, your doctor needs to evaluate any and all new Symptoms!

### References

Bruno RL, Frick NM. *Stress and "Type A" behavior as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey*. In LS Halstead and DO Wiechers (Eds.): *Research & Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Research Foundation, 1987. [[Lincolnshire](#)]

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Bruno RL, Frick NM. *The psychology of polio as prelude to Post-Polio Sequelae: Behavior modification and psychotherapy*. ORTHOPEDICS, 1991, 14(11) : 1185-1193. [\[Lincolnshire Library Full Text\]](#)

Halstead LS. *Assessment and differential diagnosis for Post-Polio Syndrome*. ORTHOPEDICS, 1991, 14(11): 1209. [\[Lincolnshire Library Full Text\]](#)

## **ABOUT DRUGS FOR PPS**

A number of drug studies were presented at the NY Academy of Sciences Symposium on PPS in April, 1994. Prednisone (a steroid) and Amantidine were tried without success to treat PPS weakness and fatigue. Growth hormone was not found to be helpful to treat new muscle weakness in one paper, but a multi-center study is beginning.

Neal Cashman again reported on the use of Mestinon to treat muscle fatigue. He found that a portion of PS whose motor nerves don't communicate well with muscles report a decrease in muscle fatigue while using Mestinon. However, the effect of Mestinon seems to wear off over time.

We presented our pilot study of a drug to treat PPS brain fatigue. In the 10% of our patients whose fatigue did not improve following the standard treatment for PPS (see above: [Exercise and Activity](#)), 60% reported less morning fatigue and less trouble staying awake on drug versus placebo. However, even if drugs are found that help, PS must still listen to their bodies and live their lives in a paced, energy conserving, Type B fashion. There is no magic pill.

## **References**

Bruno RL, Frick NM, Lewis T, Creange SJ. *The physiology of post-polio fatigue: A model for post-viral fatigue syndromes and a brain fatigue generator*. CFIDS Chronicle, 1994, 7(4): 36-42.

## **ABOUT MUSCLE TWITCHING**

In the 1985 National PPS Survey, we found that 63% of all PS report that their muscles twitch and jump as they fall asleep; 33% reported that their sleep was disturbed by twitching. This sleep disorder, called Generalized Random Myoclonus, is often only noticed by the PS's bed partner. In doing sleep studies, we found that a small dose of Ativan before bed usually stops the movements and restores sleep.

Other sleep disorders, such as sleep apnea, are not uncommon in PS. If you snore, wake not rested, with a headache or are depressed, you should talk to your doctor about a sleep study.

Many PS report another kind of muscle movement during the day: fasciculations. These are muscle twitches you can see or feel. Fasciculations are found in many non-disabled people. Usually, they are a sign, as is muscle pain, of muscle overuse. Again, talk to your doctor about any twitching.

## **References**

Bruno RL, Frick NM. *Stress and "Type A" behavior as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey*. In LS Halstead and DO Wiechers (Eds.): *Research & Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Research Foundation, 1987. [\[Lincolnshire](#)

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Bach JR and Alba AA. *Pulmonary dysfunction and sleep disordered breathing as Post-Polio Sequelae: Evaluation and management*. ORTHOPEDICS, 1991, 14(12):1329. [[Lincolnshire Library Full Text](#)]

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