



## Ultimate Burnout: Post-Polio Sequelae Basics

**Dr. Richard Louis Bruno**

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It's 8:00 p.m. and only one light is burning at corporate headquarters. Mr. Gray, MBA, the 55-year-old CEO, is awakened by the phone. He lifts his head from the desk to answer and hears his wife asking when he's coming home. Feeling as if he weighs a ton, his muscles burning, Mr. Gray wheels himself to the car and, with barely enough strength to pull his chair in behind him, drives home. He greets his kids, rolls into the bedroom, and throws himself on the bed. It's the third night this week he has gone to bed without dinner and slept in his clothes.

The alarm rings at 5 a.m. A clean suit and a cup of coffee later, Mr. Gray is on the road again. Driving to work, he thinks he hears the same faint "sizzling" sound he hears every morning--a sound like electricity arcing between two frayed wires. But on this and every other morning, he ignores the *sizzling*, ignores his increasing fatigue and muscle weakness and pain. He has a corporation to run. There's no time to "give in" to his body. But he has to wonder: "What *is* that *sizzling sound*?"

Well, Mr. Gray, that metaphoric *sizzling* is the sound of your nerves burning out. Nearly 80 percent of America's 1.63 million polio survivors hear the same sound as they, too, experience Post-Polio Sequelae (PPS). PPS are the unexpected and often disabling symptoms--new fatigue, muscle weakness, joint pain, cold intolerance--that occur about 40 years after the original bout with polio. Unfortunately, most survivors of the polio epidemics that terrorized America during the middle of this century are just like Mr. Gray: hard working, time-conscious, perfectionistic super-achievers who, as a way of life, push themselves beyond their physical limits. Like him, they ignore the *sizzling sound*, refuse to give up control, refuse to "give in" to new fatigue and weakness and pain even though their bodies are begging them to stop.

### **Post-Polio Past**

Why won't polio survivors listen to their bodies and slow down? When you understand what it was like to

have had polio, you can appreciate why they feel that "giving in" to PPS is the same as giving up their lives. "During the epidemics," says researcher Nancy Frick, a polio survivor herself, "polio was America's summer terror. The adorable March of Dimes poster children--clad in metal braces, leaning on their crutches--were everywhere saying, 'Give money to find the polio vaccine. Don't let your child become crippled like me.'"

When the polio vaccine arrived in 1954, the poster kids were needed no more. Their braces, crutches and wheelchairs were evidence of a horror that Americans wanted to forget. "So polio was eagerly forgotten by everyone," Frick says, "including those disabled by it. To be accepted back into society, polio survivors had to look 'normal' again. And since buildings were totally inaccessible, even paraplegic polio survivors had to be able to walk if they wanted to go to school or get a job."

Polio survivors were ripped away from their families for months or years and admitted to rehabilitation hospitals where they underwent multiple surgeries and draconian physical therapy. Many were verbally abused, slapped or even beaten with rubber truncheons by therapists or family members to "motivate" them to walk. "Is it any wonder that polio survivors discarded their braces and crutches when they came home from the hospital," asks Frick. "They were eager to do anything to look 'normal' and stop the abuse."

Unfortunately, polio survivors went beyond mere normalcy. Two surveys show that, regardless of the severity of their paralysis, more polio survivors marry and go to college than nondisabled Americans. They work more hours of overtime and take fewer sick days. They became the leaders of their communities and the chief executives of the world's largest corporations. That's why their nerves have started to sizzle.

## **Post-Polio Present**

PPS are not caused by the return of the poliovirus that's been hiding in the body for decades. Nor are they the result of some new disease. The simplest explanation is that polio-damaged neurons are mad as hell and are not going to take it anymore.

When polio struck, large numbers of neurons in the brain stem were damaged by the poliovirus. For those who had paralysis, the poliovirus damaged 90 percent of the neurons in the spinal cord that run the muscles; nearly half of those neurons died. The surviving but damaged neurons are less able to manufacture acetylcholine, the chemical that neurons release to make muscles contract. Yet the damaged neurons sent out sprouts--like extra telephone wires--to turn on muscle fibers orphaned when their motor neurons were killed by the poliovirus. This sprouting allowed many people who were totally paralyzed during the initial polio attack to actually walk out of the hospital some months later.

But since these polio-damaged and over-sprouted motor neurons have been doing double and triple duty for 40 years, even polio survivors with minimal loss of function have been heading for a fall. "Sprouted motor neurons can no longer make muscles contract as forcefully as they once did, or for as long as they once could, because their damaged internal chemical factory is failing after years of overworking," says Kessler Institute for Rehabilitation physiatrist Jerald Zimmerman. "Muscles become weaker and hurt as they try to do more work than they are able to do. And because weakened muscles can no longer support the joints, polio survivors' shoulders and elbows ache and their knees start to bend backward." Standing, walking, lifting, pushing a wheelchair--sometimes swallowing and breathing, especially in those who had respiratory polio--become more difficult and more painful.

While new muscle weakness and pain are reported by more than 75 percent of polio survivors, the most common PPS symptom is fatigue. Fully 91 percent of polio survivors report two kinds: "body fatigue" and

"brain fatigue ." Body fatigue is the feeling that you weigh a ton and that the longer you use your muscles, the more they lose strength. "Because of new muscle weakness, many polio survivors expend as much energy just getting up and dressed and out to work in the morning as does a marathon runner," says Lauro Halstead, Post-Polio Program director at Washington's National Rehabilitation Hospital. "Why wouldn't they feel fatigued?"

Brain fatigue is the feeling that you can't focus your attention, can't concentrate on what you're reading and can't stay awake as the day goes on. Researchers at Kessler Institute have recently found that polio survivors with brain fatigue do in fact have significantly impaired attention and are not able to release the brain-stimulating hormone ACTH in response to stress. MRI scans of fatigued polio survivors have found damage in the brain areas that control wakefulness and attention, the same areas that were damaged by the original poliovirus infection.

## **Post-Polio Future**

With the coming of PPS, the future might sound bleak for polio survivors. Both the March of Dimes Birth Defects Foundation and the U.S. Congress have refused to set aside funds for PPS research. "In spite of this, much has been learned about the cause and treatment of PPS," says Paul Peach, medical director of Georgia's Roosevelt Warm Springs Institute for Rehabilitation. "The future is much more optimistic than had been expected." Two recent studies have identified drugs that may decrease PPS fatigue. Neil Cashman of the Montreal Neurological Institute found that Mestinon, a drug that prevents the breakdown of acetylcholine in the muscle, may reduce body fatigue in some polio survivors. A just-completed study from Kessler Institute found that Parlodel, an anti-Parkinson's disease drug, helped to increase attention and wakefulness and reduce post-polio brain fatigue.

But Peach warns that using drugs to treat PPS may be dangerous. "Weakness and fatigue are the body's way of telling polio survivors to rest," he says, "like a fuse that blows when their nerves are overworked." Peach worries that using these drugs will be like putting a penny in the fuse box , allowing polio survivors to do even more harm to polio-damaged neurons.

But, neither Mestinon nor Parlodel is effective if polio survivors don't follow **The Golden Rule** for the treatment of PPS: "**If what you do causes pain, fatigue or weakness, don't do it!**"

The Golden Rule does not mean that polio survivors should sit home and become couch potatoes. The Golden Rule does mean that polio survivors should stop exhausting themselves, especially with regard to exercise. Many survivors are prescribed--or actually ask for--the kind of physical therapy they had right after polio: exercising to the point of exhaustion. But several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength. No free weights, exercise bikes, tread mills, NordicTracs or Thighmasters for polio survivors. "Feeling the burn" means nerves are burning out.

Stretching, however, helps decrease pain and increase range of motion. And gentle, non-fatiguing exercise can be useful for some survivors to help maintain muscle strength and tone, especially after getting a new brace.

Many studies show that changing survivors' physically and emotionally stressful lifestyle is the best way to reduce weakness, fatigue and pain. On[e study] by James Agree at the University of Wisconsin shows that polio survivors who pace activity--that is work and then rest for an equal amount of time--can do 240 percent more work than if they push straight through the task. Another study shows that survivors use three times less energy in walking if they use a short brace on a weakened leg. And the follow-up study of

Kessler's six-week program of behavior modification and physical and occupational therapy shows that polio survivors who comply with treatment --pace activities, conserve energy, take two 15-minute rest breaks a day, and use assistive devices (a brace, cane, crutches, wheelchair or scooter)--have up to 22 percent less pain, weakness and fatigue 18 months after therapy ends. But survivors who quit therapy have 21 percent more fatigue and 76 percent more weakness 18 months after leaving the program.

And there's the rub. It's only the refusal to listen to that *sizzling sound* that causes PPS to continue or progress. That's why behavior modification and psychotherapy are required to help survivors accept their second bout with polio, change their super-achieving lifestyles and deal with the fear of looking disabled. "There will be no magic pill to cure PPS," says Paul Peach. "But by making lifestyle changes and eliminating 'overuse abuse,' progressive fatigue, weakness and pain can be substantially reduced or eliminated."

As Mr. Gray knows well, this whole PPS business stinks. But isn't it far better to accommodate to PPS now than to be forced to give up your entire life because you are too weak and fatigued to function? I know, you'll slow down and take care of yourself "when you're ready." You'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons? Isn't it time to listen to the *sizzling sound*? Isn't it time to take care of yourself? To paraphrase one famous paraplegic polio survivor who refused to take care of himself, "You have nothing to fear but fear itself."

## Red Flags for Polio Survivors

**[Mis]Diagnosis:** Many polio survivors have been incorrectly told they cannot have PPS because they didn't have paralytic polio. The National Institute of Health has just studied pairs of identical twins, one who had paralytic polio and one who had non-paralytic polio. Seventy-one percent of those who had paralytic polio have PPS. The surprise is that 42 percent of those who had non-paralytic polio also have PPS. The lesson: Don't let a doctor tell you it's all in your head just because you didn't have paralytic polio.

**Anesthesia:** Polio survivors are anesthetized very easily because the part of the brain that keeps you awake was damaged by the poliovirus. They also stay anesthetized longer and can have significant complications from anesthesia. Even nerve blocks with local anesthetics can cause problems.

All polio survivors should have lung function tests before having a general anesthetic. "Polio survivors with a lung capacity below 70 percent may need a respirator or respiratory therapy after surgery," says Augusta Alba of New York's Goldwater Memorial Hospital. Your complete polio history and any new problems with breathing, coughing or swallowing should be brought to the attention of your surgeon or dentist--and especially your anesthesiologist--long before you go under the knife. Also, polio survivors should *not* have same-day surgery.

**Pain:** Two studies have shown that polio survivors are twice as sensitive to pain as everyone else and need more pain medication for a longer time after surgery or an injury. However, survivors have had to develop an extremely high pain tolerance to deal with their increased pain sensitivity and are not likely to become addicted to pain medications.

**Sleep:** The majority of polio survivors have trouble sleeping due to pain, anxiety or sleep disorders, such as sleep apnea or generalized random myoclonus. GRM occurs when muscles in different parts of the body twitch and jump throughout the night. Amazingly, most polio survivors aren't aware that they stop breathing or twitch. If you awaken with a headache, with your heart pounding, short of breath or don't feel

rested in the morning, call a local sleep disorders center for a sleep study.

## Resources

Orthopedics, November and December, 1991.

These special issues provide all the information needed to start a PPS clinic. A must read for anyone who treats polio survivors.

[Harvest Center, Inc.](#), 151 Prospect Ave., Hackensack, NJ 07601; [\(201\)342-6777](tel:(201)342-6777).

Provides the 1995 Audio Symposium for PPS, four audio taped lectures on the cause and treatment of PPS and the psychology of polio. Also available is the Computerized Assessment Program for PPS. After a brief questionnaire, the computer suggests possible causes, tests and therapies for new symptoms and lists the world's medical literature on PPS.

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**The Secretary, Lincolnshire Post-Polio Network**

**PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom**

**Telephone: [+44 \(0\)1522 888601](tel:+44(0)1522888601)**

**Facsimile: [+44 \(0\)870 1600840](tel:+44(0)8701600840)**

**Email: [info@lincolnshirepostpolio.org.uk](mailto:info@lincolnshirepostpolio.org.uk)**

**Web Site: [www.lincolnshirepostpolio.org.uk](http://www.lincolnshirepostpolio.org.uk)**

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