

THE POST-POLIO LETTER

Basic facts about PPS for polio survivors' doctors, family & friends.

Dr. Richard L. Bruno

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WHAT ARE POST-POLIO SEQUELAE?

Post-Polio Sequelae (PPS, Post-Polio Syndrome, The Late Effects of Poliomyelitis) are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of "non-paralytic" polio survivors. There are about 2 million North American polio survivors and 20 million polio survivors worldwide. The existence of PPS has been verified by articles in many medical journals, including The Journal of the American Medical Association, the American Journal of Physical Medicine and Rehabilitation and The New England Journal of Medicine.

WHAT CAUSES PPS? PPS are caused by decades of "overuse abuse." The poliovirus damaged 95% of brain stem and spinal cord motor neurons, killing at least 50%. Virtually every muscle in the body was affected by polio, as were brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out "sprouts," like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These over sprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

HOW ARE PPS DIAGNOSED? There is no diagnostic test for PPS, including the electromyogram (EMG). PPS are diagnosed by excluding all other possible causes for new symptoms, including abnormal breathing and muscle twitching that commonly disturb polio survivors' sleep, a slow thyroid and anemia. Other neurological or muscle

ARE PPS LIFE THREATENING? No. But because of damaged brain activating neurons polio survivors are extremely sensitive to, and need lower doses of, gas and intravenous anesthetics and sedative medication. Polio survivors can have difficulty waking from anesthesia and can have breathing and swallowing problems, even when given a local dental anesthetic.

IS PPS A PROGRESSIVE DISEASE? PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work with too few poliovirus - damaged, oversprouted neurons. However, polio survivors with untreated muscle weakness were found to lose about 7% of their remaining, overworked motor neurons each year.

IS THERE TREATMENT FOR PPS? Yes. Polio survivors need to "conserve to preserve," conserve energy and stop overusing and abusing their bodies to preserve their abilities. Polio survivors must walk less, use needed assistive devices -- braces, canes, crutches, wheelchairs -- plan rest periods throughout the day and stop activities before symptoms start. Also, since many polio survivors are hypoglycemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low-fat / higher-protein meals during the day.

ISN'T EXERCISE THE ONLY WAY TO STRENGTHEN WEAK MUSCLES? No. Muscle strengthening exercise adds to overuse. Pumping iron and "feeling the burn" means that polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful. But whatever the therapy, it must not trigger or increase PPS symptoms.

IS TREATMENT FOR PPS EFFECTIVE? Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring for themselves, slowing down and especially with "looking disabled" by asking for help and using assistive devices.

WHAT CAN DOCTORS, FAMILY AND FRIENDS DO TO HELP? Polio survivors have spent their lives trying to act and look "normal." Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should not do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn't take control of polio survivors' lives. Neither gentle reminders nor well-meant nagging will force polio survivors to eat breakfast, use a cane or rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it

Whether you had polio or not, please COPY and MAIL this letter to your doctors. With your help every doctor will learn about the cause and treatment of PPS and give polio survivors the care we so desperately need. Thank you!

Mia Farrow, polio survivor

Thaddeus Farrow, polio survivor

Co-Chairpersons **The POST-POLIO LETTER Campaign**

**For more information about the cause and treatment of PPS go
to www.postpolioinfo.com**

POLIO SURVIVORS ARE NO LONGER POSTER CHILDREN.

We are accomplished adults who are being disabled by POST-POLIO SEQUELAE, new fatigue, weakness and pain, affecting the world's 20 million polio survivors.

Yet most doctors don't know PPS exists. Please go to: www.postpolioinfo.com print and then mail THE POST-POLIO LETTER to your doctors.

With your help every doctor will learn about PPS and give polio survivors the care we so desperately need.

Thank you!

Mia Farrow
Thaddeus Farrow
Co-Chairpersons, The POST-POLIO LETTER Campaign

Please, bring this to your local newspaper and ask them to print this public announcement.

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

FULL NAME:		DATE OF BIRTH:
PHONE NUMBER:	CURRENT HOME ADDRESS:	
EMAIL ADDRESS:	THERAPIST:	
REFERRAL SOURCE:	CURRENT GP:	
NEXT OF KIN:	ACC/NHI NUMBER:	

Questions about your Accommodation and Care Needs

WHAT IS YOUR OCCUPATION?

Full Time
 Part Time
 Casual
 Retired
 Pension

AVOCATIONAL / LEISURE INTERESTS:

WHAT TYPE OF ACCOMMODATION DO YOU RESIDE IN:

House/Unit
 Retirement
 Nursing Home
 Other

IF 'OTHER' WAS SELECTED, PLEASE DESCRIBE FURTHER:

DO YOU NEED HELP WITH YOUR PERSONAL CARE:

No
 Yes

IF 'YES' WAS SELECTED, PLEASE DESCRIBE FURTHER:

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

WHO HELPS YOU?

- Partner Family Community Services Residence Services

General Health and Activity

PLEASE TICK IF YOU HAVE ANY OF THE FOLLOWING:

- | | |
|---|---|
| <input type="checkbox"/> Heart Condition | <input type="checkbox"/> Depression |
| <input type="checkbox"/> High Blood Pressure | <input type="checkbox"/> Anxiety |
| <input type="checkbox"/> Pacemaker | <input type="checkbox"/> Sleep Disturbance |
| <input type="checkbox"/> Low Blood Pressure | <input type="checkbox"/> Metal Implants |
| <input type="checkbox"/> Venous Condition | <input type="checkbox"/> Visual Impairment |
| <input type="checkbox"/> Kidney Problems | <input type="checkbox"/> Hearing Impairment |
| <input type="checkbox"/> Chronic Lung Disease | <input type="checkbox"/> Currently Smoking |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Fall (in the last 12 months) |
| <input type="checkbox"/> Osteoporosis | <input type="checkbox"/> Hospitalised (in the last 12 months) |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Pain (Acute / Chronic) |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Neurological Condition |
| <input type="checkbox"/> Infectious Disease | |

IF 'NEUROLOGICAL CONDITION' WAS SELECTED, PLEASE DESCRIBE FURTHER:

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

Questions about Polio

How old were you when you were diagnosed with polio?
Where were you living at the time of diagnosis?

How did the polio effect your body?

Was there respiratory muscle involvement?
Was ventilation required?

Do you know how long you were paralysed for?
How long were you in hospital?

When you returned home were you still weak? If so, in what areas
of your body?

After leaving hospital, did you receive physiotherapy and
for how long?

Do you know how long, after getting polio could you walk?
Did you wear splints?

Did you require wheelchair use at any stage?

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

What braces/devices did you use to walk with? How long were they used for?
Could you participate fully at school?

Did you have any reconstructive surgical procedures?
Do you have any other past medical history/co-morbidities that you think would be worth us knowing about?

Current Situation and Impairments

WHICH OF THESE SENTENCES BELOW BEST DESCRIBES YOUR PRESENT SITUATION:

- I am stable at present, but I am worried issues may arise.
- I have declining function but it is occurring slow.
- I have experienced a sudden or severe decline in function.

PLEASE DESCRIBE IN DETAIL THE FOLLOWING:

1. If you experienced a decline, when did you first notice it?
2. How many years do you think your condition was stable for?
3. What has changed in recent years?

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

Rivermead Mobility Index

Task	Score 1 = Yes 0 = No	Describe in Detail (Expand on aids / orthotics if required).
Turning Over in Bed: Do you turn from your back to your side without help?		
Lying to sitting: From lying in bed, do you get up to sit on the edge of your bed on your own?		
Sitting Balance: Can you sit on the edge of the bed without holding on for 10 seconds?		
Sitting to Standing: Can you stand up from any chair in less than 15 seconds and stand there for 15 seconds, using hands and/or an aid if necessary?		
Standing Unsupported: Can you stand for 10 seconds without any aid?		
Transfer: Do you manage to move from bed to chair and back without any help?		
Walking Inside: Can you walk 10 metres, with an aid if necessary, without standby help?		
Walking Inside: Can you walk 10 metres, with no aid/caliper/splint (including walls/furniture) without standby help?		
Stairs: Can you manage a flight of stairs without help?		
Walking Outside: Can you walk outside, on even pavements, without help?		
Walking Outside: Can you walk outside over uneven ground (grass, gravel, snow, ice etc) without help?		
Picking up off floor: Can you manage to walk 5 metres, pick something up from the floor and then walk back without help?		

Pre-Assessment Form Post Polio Syndrome and Late Effects of Polio

Bathing: Do you get into/out of the bath or shower and to wash yourself unsupervised and without help?		
Up and down 4 steps: Do you manage to go up and down four steps with no rail, but using an aid if necessary?		
Running: Can you run 10 metres without limping in four seconds (fast walk, not limping, is acceptable)?		

TICK WHAT YOU WOULD LIKE TO DISCUSS IN THE ASSESSMENT:

- | | |
|---|---|
| <input type="checkbox"/> My Pain | <input type="checkbox"/> Help with sleep hygiene |
| <input type="checkbox"/> My Fatigue Management | <input type="checkbox"/> My Walking |
| <input type="checkbox"/> Gain more education - self and family | <input type="checkbox"/> Tasks I am finding difficult |
| <input type="checkbox"/> Advice on diet, nutrition and swallowing | |

PLEASE DESCRIBE FURTHER:

HOW WOULD YOU RATE YOUR LIFE AT PRESENT?

- 1 2 3 4 5 6 7 8 9 10
 Poor Excellent



Exercise: Use it and Lose it

By Dr. Richard L. Bruno HD, PhD

Director, International Centre for Polio Education

www.postpolioinfo.com

Question: I read that you don't recommend exercise for polio survivors who are getting weaker. But if I stop exercising and do nothing, won't I lose muscle tone, get flabby and become deconditioned and even weaker?

Answer: You're asking a good question but are using buzzwords that Americans hear on infomercials. It's vital that polio survivors understand what the research really says about exercise for newly weakened muscles and know the definitions of "muscle tone" and "deconditioned." We never tell polio survivors to "do nothing." Both The Post-Polio Institute and Warm Springs long-term follow-up studies find the same thing. All PPS symptoms, fatigue, pain and muscle weakness, decrease when polio survivors stop exercising and follow The Golden Rule:

If anything causes fatigue, weakness or pain, DON'T DO IT! (Or do much less of it.)

Unfortunately, those who recommend strengthening exercise to polio survivors quote from the conclusions of half a dozen small studies of leg muscle strengthening, apparently without having read them critically. The studies' conclusions say that exercise programs "lead to significant gains in strength." However, when you look at the responses of individual subjects the "significant gains in strength" are hard to find. Just over half of the studies' subjects had an increase in upper leg muscle strength of about 26%. One quarter had no change in strength while 21% actually had a decrease in strength of about 10%. So almost as often as not exercise either had no effect or actually decreased muscle strength.

What's more, only two studies asked whether exercise affected polio survivors' fatigue and their ability to function in their daily lives. In one study, strength increased by 36% but muscle fatigue also increased by 21%. In the other study, although muscle strength increased by 30%, there was no improvement in polio survivors' ability to do daily activities, and muscle fatigue increased as much as 300%! You have to ask what good comes from any small percentage increase in muscle strength that is not related to improved functional ability and that actually increases muscle fatigue more than strength.

And what of "muscle tone"? Most people think that muscle tone means muscles that are firm and have a nice shape. Muscle tone actually means that muscle fibers are ready to contract. Muscle tone is lost when motor neurons are damaged and can't turn on muscle fibers. Loss of tone can happen when polio survivors exercise too much and muscles become weaker when poliovirus-damaged motor neurons fail. Remember, PPS researcher Alan McComas found that polio survivors who have muscle weakness lose at least 7% of their motor neurons each year. This is why he concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

Polio survivors' muscles get smaller lose tone if they're overused and the motor neurons that turn on the muscle fibers die. Arms and legs get flabby because of increased fat deposits, not a loss of muscle tone. Exercise does burn fat and at first causes muscles to increase in size. But polio survivors don't want bigger muscle fibers because they "further stress metabolically damaged neurons that are already overworking." The best way to prevent flabby arms and legs is to stop overusing and abusing your motor neurons and to follow the higher protein, low fat and lower carb Post-Polio Diet.

And what does "deconditioned" mean? Many polio survivors believe that there are only two ways to live: overusing and abusing or being a couch potato and becoming "deconditioned." Deconditioning is something that happens when astronauts live in space or you put someone to bed for weeks, removing the pull of gravity and causing a decrease in blood volume and blood pressure. Deconditioning can only happen if polio survivors never leave the couch, not if they take two daily rest breaks on the couch, take a ninety minute nap, stop strengthening exercising or use a power wheelchair.

However, polio survivors may need to "condition" their hearts, especially if they have had a heart attack. "Cardiopulmonary conditioning" uses exercise to strengthen the heart muscle (which was not affected by polio) and make it work more efficiently. However, there is no benefit to running on a treadmill or riding a bicycle to exercise the heart if you thereby stress and kill off poliovirus-damaged motor neurons. Some polio survivors can do heart conditioning by using their less affected limbs, usually their arms, in a carefully monitored program of paced and non-fatiguing exercise. But for many this type of exercise doesn't increase heart rate enough to get a conditioning effect and leads to fatigue and muscle weakness so it can't be continued for more than a few sessions.



Muscle Cramps and Muscle Spasms

A Bruno Byte

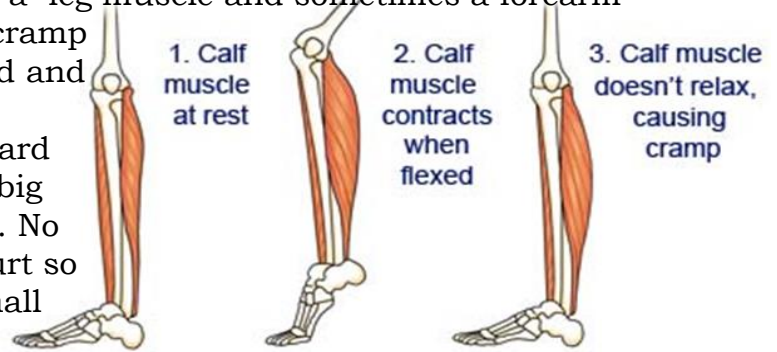
From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

What is the Difference Between a Muscle “Cramp” and a Muscle “Spasm” ?

A muscle CRAMP is a short-lived, very painful, involuntary contraction of an entire muscle or a relatively large portion of a muscle, usually a leg muscle and sometimes a forearm muscle. Who hasn't had a screamingly painful cramp of the calf muscle that pulls your toes downward and forces you to stand to stretch it out?

A muscle SPASM feels hard, sometimes as hard as bone, and can be as small as an M&M or as big as the entire side of your neck or your low back. No one knows what spasms are or why they can hurt so badly! Spasms seem to be muscle fibers in a small area contracting into a dense knot and usually

occur in postural muscles in the neck and back. But, in my 1990 study, there was NO relationship between “hard” a muscle spasm was, muscle electrical activity and pain. So, a small, not-so-dense spasm in a neck muscle can cause a headache that puts you in bed for hours. But a large, dense rock of a spasm in your neck or back may not hurt at all even when a physical therapist puts her thumb in it.



A Question on the topic of Muscle Spasms upon Wakening (7/30/2017)

Original Post: When I wake up at night or in the morning with my neck, legs and back muscles in painful spasm. I have to stretch and make my arms and legs stretch as much as I can. I have to do this two or three times and showers before I can move.

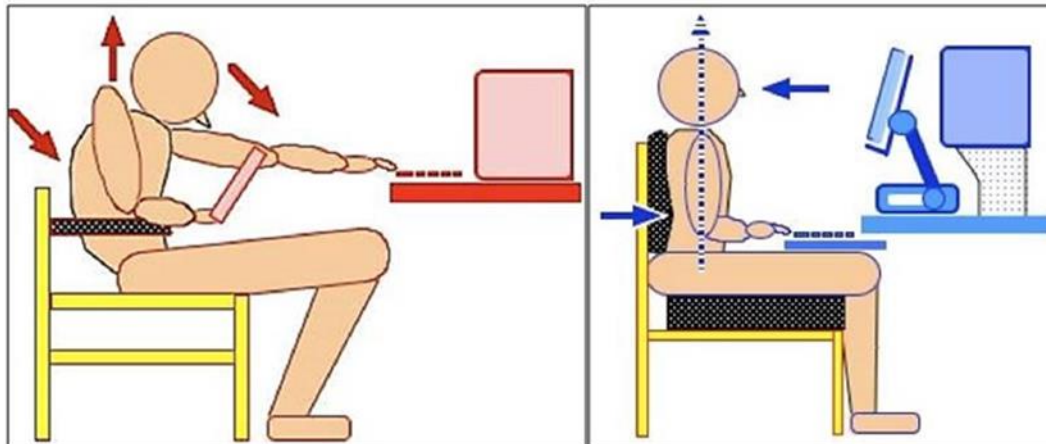
Dr. Bruno's Response: Painful muscle spasms when you wake from sleep in the morning, which usually happens during REM (dream) sleep when your brain actually paralyzes your muscles, sounds like another polio paradox. But the clue as to why muscles go into spasm after you wake lies in the brain's ability to control your motor neurons and your muscles. Spinal cord motor neurons are like misbehaving, stubborn children. They want to make muscles contract all the time. It's what motor neurons do! But, to prevent the "kids" from doing what they want their "parent," the brain, sends signals to the spinal cord telling the kids when and how much they should turn muscles on, and, as important, turn muscles off. If something interferes with the signal to turn muscles off - like a sleeping, poliovirus-damaged brain -- the kids indeed do what they want: They turn muscles on! And when they are turned on for too long you get rigid muscles and painful spasms come morning.



You can see the result of this brain/spinal cord disconnection in a condition that polio survivors know well: leg movements in sleep. Poliovirus-damage to **brain muscle control neurons prevents** the sleeping brain from automatically sending a "turn off" signal to the spinal cord and allows motor neurons to do what they want: Contract! Our studies of sleep in polio survivors found that these contractions don't just happen in leg muscles but can happen in muscles anywhere -- arms, abdomen, chest and, maybe most painfully, the back and neck.

How do you prevent sleep spasms? Since alcohol turns brain output signals down, you shouldn't drink in the evening. Over using your muscles during the day "irritates" poliovirus-damaged motor neurons and makes them more likely to cause those muscles to contract.

Stretching and painless posture (see below) during the day, stretching and a hot bath before bed and keeping the muscles that spasm warm while you sleep (using a heating pad with an automatic shut off or a little dab of Capzasin also can help.



PAINFUL Posture

PAINLESS Posture

In our experience at the Post-Polio Institute, the most effective treatment is 0.5 - 2.0 mg of alprazolam (Xanax) 30 minutes before bed. Alprazolam, like its grandfather diazepam (Valium), directly turns off spinal cord motor neurons during sleep when the post-polio brain can't. We hope your doctor won't say "No" to alprazolam because "it's addictive." The potentially addictive effect of the drug -- relaxation -- occurs when you can't feel it, i.e., during sleep. Alprazolam is a Valium-like drug that directly quiets the spinal cord motor neurons that cause your muscles to twitch at night. In 30+ years, we never have had a Post-Polio Institute patient become addicted to alprazolam or even require higher doses over time. Once the right dose is found, that's the dose the polio survivors' stay on. Sweet spasm-free dreams!

Bottom line: Polio survivors' muscle OVERUSE and muscle MISUSE (like painful posture) causes cramps.

See the [POLIO SURVIVORS HANDBOOK](http://postpolioinfo.com) at postpolioinfo.com for chapters on preventing cramps and spasms.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of [Dr. Richard Bruno's](#) articles, monographs, commentaries and "Bruno Bytes"
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The Psychology of Treating PPS

A Bruno Byte

From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

There is no question that the biggest obstacle to treating PPS is polio survivors' fear of change. From our 1995 International Post-Polio Survey we know that polio survivors experienced 34% more physical abuse and 94% more emotional abuse as kids just because they looked disabled. As so many patients have said to me, "Why would I want to (insert any change in activity or use of any assistive device) look disabled and be abused and rejected *again*?"

So, the challenge in managing PPS is dealing with what's going on from the neck up, more even than the neck down. After 36+ years and treating thousands of people with disabilities, I've found some tips and techniques to help patients deal with their powerful feelings that can prevent a physical disability from becoming an emotional one.

"Irritability Is Not An Emotion." When something life changing happens, like becoming disabled, people often have trouble knowing what they feel, let alone being able to express their emotions. Sometimes folk know what they feel but believe they are burdening their families and friends by talking about feelings. But, strong emotions don't go away or remain hidden. Feelings make themselves known whether or not you're aware of them or you want them to, often as irritability. If you are irritable -- nasty as a rattlesnake, sniping at your spouse, and kicking the cat -- there is a powerful emotion inside of you that's trying to get out. Better to tell someone what you feel, or even say that you don't know what you feel, than to be irritable. Looking for feelings underneath the irritability and talking about them not only helps you feel better, by bringing the feelings into the light where you can deal with them, but also helps your family, friends and pets feel less like they're living near Mount Vesuvius.

"The Stages Have Left Town." Once you get beyond being irritable and know what you're feeling, what do you do? Do you remember the "stages of acceptance" of dying: denial, anger, bargaining, depression and acceptance? These stages have been applied to losses other than dying, including having a disability. The problem is that there is no sequence of "stages of acceptance" for dying or for disability. People don't neatly move from denial through to acceptance. Some folk can go from a rehab hospital bed to acceptance, while others flip from acceptance to denial and can experience everything in between in any order. What's important is that we're not forced to fit emotional stages but are free to feel what we feel, when we feel it.

We also shouldn't accept labels for our emotions. Sadness, fear, helplessness and hopelessness are often all labeled as "depression" by doctors. Too often patients are given an antidepressant and sent on their way. It's far better to work with a psychotherapist to deal with your specific feelings than to accept a label, take a pill and hope the "bad" feelings disappear. Depression is a medical illness and can be treated with antidepressants. But, when depression is gone, your feelings remain and will still have to be dealt with.

"It is Better to Curse the Darkness Than to Light A Thousand Candles." Back in the early 1970s, future MS'er Richard Pryor was pilloried for using profanity in his comedy. "Why does he have to use

'four letter words'," whined mothers across America?

Pryor used "four letter words" because he was describing 300 years of abuse. What was he supposed to say, "Oh darn, my great-great-grandfather was kidnapped and stuck in the hold of a slave ship and, shoot, he and his family were forced to pick cotton for generations, and heck, they were beaten and hanged asking for basic civil rights?"

Darn, shoot, and heck didn't do it for Pryor and they don't do it for most people with disabilities. Having a disability stinks. If you're lucky, you'll learn from the experience and grow. But, I think people with disabilities, and especially their shrinks, should acknowledge that disability bites and say so.

I have found that one good "damn" is worth a thousand "darns." Profanity vividly communicates pain and sadness while releasing frustration and anger. So, if my patients curse, I curse right along with them. I sometime curse on my own to make a point or to help break a patient's feelings lose. A well-placed "damn" or "hell" gets let's patients know that they that can feel and express anything they feel.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of [Dr. Richard Bruno's](#) articles, monographs, commentaries and "Bruno Bytes"
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Should Polio Survivor's do Exercise for Strengthening ? **No Way!**

A Bruno Byte

From Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

Question: In January I shoveled snow and my left leg became very weak. My knee buckled twice but I caught myself before I fell. I went to my doctor and he sent me right to physical therapy. In the first session I was on the treadmill for 10 minutes, on the bike for 5 and I did straight leg raises with weights around my ankles. I barely made it home, where I fell to the kitchen floor. My legs are even weaker now and they are always burning. Don't polio survivors need exercise to make weak muscles stronger?

Dr. Bruno's Response: Your body is answering that question for you, but let me tell you about the research regarding exercise and polio survivors. There have only been about half a dozen small studies that tested around 12 subjects each. And although 90% of the subjects were said to have "Post-Polio Syndrome" or reported new muscle weakness, their legs were much stronger than yours. Subjects were able to ride a bike for 5 minutes and then do straight leg raises multiple times with a weight attached to the ankles 2 to 4 times a week for from six weeks to two years -- something you couldn't do **one** time. The studies tested polio survivors' ability to strengthen their quadriceps muscle, the muscle in the front of your upper leg that allows you to kick your lower leg up while you're sitting and to "lock" your knee when you're standing. The quadriceps is the muscle that gave out when you fell in the kitchen.

The studies differed in the way exercises were performed. Two studies asked polio survivors to limit the number of leg lifts if they felt fatigue, told them to rest between bouts of exercise and increased the amount of weight lifted only if there was no "excessive fatigue." Other studies described their exercise regime as "high-intensity," "heavy resistance," or "aggressive." Two studies required polio survivors do five minutes on an exercise bicycle before they did as many as 30 leg lifts three times each week. In the most aggressive study polio survivors did five minutes on the bicycle followed by a 60 minute exercise class twice a week for 5 months! A polio survivor who is able to do that kind of exercise clearly does **not** have PPS!

The subjects in the studies had more strength, more endurance, more ability to function and fewer symptoms than you do or do the patients we treat at The Post-Polio Institute. Still, when you read the researchers' conclusions it sounds like exercises is just the thing to restore muscle strength in polio survivors with PPS. Said one article, "...a supervised training program can lead to significant gains in strength."

Unfortunately, when you look at the study's actual data, the benefits of exercise are far from clear. Only 53% of those who exercised had an increase in leg muscle strength of about 26%. About one quarter of the subjects had no change in strength while 21% had a **decrease** in strength of about 10%. So, more often than not, exercise either had no effect or actually decreased muscle strength.

But there's more. Well, actually less. Only three studies asked whether exercise had an impact on polio survivors' ability to function in their daily lives. In one study where exercise was limited by fatigue, there was no measurable change in muscle strength over 2 years, although half of the subjects thought their walking and stair climbing had improved. In one aggressive study there was a

29% muscle strength increase, no improvement in subjects' ability to do their daily activities, but an increase in muscle **fatigue** of from 150% to 300%! Muscle fatigue also increased by 21% in another aggressive study in which strength increased by 36%. You have to ask what good comes from any small increases in muscle strength that are not related to improved functional ability but **are** related to muscle fatigue that increases more than strength does.

[Dr. Alan McComas'](#) performed a study showing that polio survivors who were not treating their muscle weakness and were getting weaker lost 7% of their motor neurons each year. McComas concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking." Muscles weakness is a sign of neurons failing and dying. Polio survivors were taught to "use it or lose it" and to exercise until you "feel the burn." When you feel the burn you are burning out your neurons.

The Bottom Line: Should you do exercise to strengthen newly weakened muscles? No!

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“Transient” Muscle Weakness

A Bruno Byte

From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

Question: If the accepted theory of post-polio muscle weakness is that our motor neurons are dying, why do I improve with rest after having a period of severe weakness when I overdo? Even though I can become completely lame, the loss is temporary if I rest up for a day or a week.

Dr. Bruno’s Response: You’re describing a symptom that PPS researchers have totally ignored: “transient weakness.” We call it “New Year Syndrome.” Polio survivors complain that their muscles become significantly weaker -- even paralyzed -- in late December after they have done too much Christmas shopping; but strength returns in January after they rest.

Something dangerous is happening to cause the *transient* weakness of “New Year Syndrome.” Remember that the poliovirus killed off at least 50% of your motor neurons. The neurons that weren’t killed were damaged by the poliovirus but were able to sprout -- send out extra “telephone lines” -- to talk to the muscle fibers that were orphaned when their motor neurons died. After polio you were left with less than half of your [motor neurons](#) -- neurons that not only are over-sprouted, but also have cell bodies that are smaller than normal, have damaged protein-making “factories” and have been severely overworked for the past 50 years. When you experience transient weakness you have overloaded your neurons’ protein-making factories and drained their energy reserves. After you rest, the neurons’ protein supply increases and you are able to turn on your muscles again.

But every time you drain your motor neurons, we think you are doing damage that eventually causes permanent weakness as the repeatedly drained neurons die. Think of what would happen to your car battery if you left the headlights on every night. You get up the first morning and your battery is flat. You jump-start the battery and drive off. The next night you leave the lights on, jump-start the battery again, and drive away. After about a week the battery will no longer take a charge and you won’t be driving anywhere!

Canadian PPS researcher [Alan McComas](#) found that polio survivors who are getting weaker over time lose 7% of their motor neurons per year, that’s 7% *on top of* the 50% they have already lost! Prevent transient weakness -- and thereby prevent permanent weakness -- by resting before your muscles become weak, let alone become completely paralyzed!

Remember: You can replace your car’s battery but you can’t replace your motor neurons.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of [Dr. Richard Bruno’s](#) articles, monographs, commentaries and “Bruno Bytes”
<https://www.papolionetwork.org/encyclopedia.html>

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