



Bruno Bytes – September, 2015 (Bits and Tidbits from the Post-Polio Coffee House)

On the topic of being a “True” Polio Survivor (9/30/2015)

Original Post: After 77 years of polio I think I am A Veteran Polio Survivor.

Dr. Bruno’s Post: A "TRUE Survivor" is someone who accepts the truth that they had polio, have PPS and is committed to listening to their body and taking care of themselves instead of everyone else in the world. I think a survivor is someone who had the guts to make it through the war to become a veteran!
The words don't matter as long as we keep fighting!

On the topic of “Functional Capabilities Evaluation” for Long Term Disability 9/30/2015

Original Post: I need some help. My long-term disability carrier is requiring that I have the following tests for my 2 year evaluation:

- 1) Functional Capabilities Evaluation (FCE)
- 2) Neuropsychological Evaluation

I am worried about the pain after the FCE. Any words of advice and has anyone been required to take these tests and your outcome with the long-term carrier (approval/denial).

What IS FCE ? http://www.ehow.com/info_7778411_functional-capacity-evaluation.html

Dr. Bruno’s Response: I removed FCE and Neuropsychological testing from the Social Security ruling for PPS because:

- 1) Polio survivors can push through and do OK then crash for 4 days in bed
and
- 2) The pushing and crashing causes Damage and is Medically Contraindicated.

Have your doctor write a letter to the insurance company saying:

- 1) The published medical literature finds that FCE and Neuropsychological testing are NOT helpful in diagnosing PPS,
- 2) Such testing further damages already compromised neurons and,
- 3) FCE and Neuropsychological testing are therefore MEDICALLY CONTRAINDICATED. Not even the Social Security Administration allows, let alone requires, such strenuous testing.

Set your browser to <http://www.PostPoliInfo.com> for the Social Security Ruling for PPS.

On the topic of using a “sitting” exercise CD (9/30/2015)

Original Post: Does anyone have a recommendation for an exercise CD? There are so many seated exercise CDs. Does anyone have any recommendations?

Dr. Bruno’s Response: Just do your daily activities. You don't need muscle tone you need muscles that work. Exercise is the surest way to kill off the nerves that run your muscles. You need to go to the post- polio library at www.postpolioinfo.com and start reading about PPS.

Not only is cardio exercise counterproductive and will cause PPS muscle weakness by burning out the surviving, overworked neurons, the overwhelming majority of polio survivors can't get their heart rate up high enough to actually get a cardiopulmonary effect. It's like paying good money for high-quality gin, getting home and finding out that it's wood alcohol! NO heart pumping exercise!

Additional Post: I used to love to swim but it has become harder and harder, firstly because I am unbalanced through having a mastectomy in 2004 and secondly because I have such awful oedema in my legs they float in the bath... my question is do you think swimming is counterproductive for my motor neurons.

Dr. Bruno's Response: Just the getting there, changing clothes, showering -- let alone the swimming -- make swimming too much to do. Coming back into the locker room to change? It's never warm enough.

On the topic of Muscle Pain and using a "TENS" unit (9/26/2015)

Original Post: I had a bad flair up and all my muscles are hard and like a brick almost as if they are all the same. A friend of mine brought me over a TENS Unit to use and I have it set on 2 and my whole muscle by my shoulder blade has been in an off and on spasm, not a little but it must be the whole muscle. Is this a good or bad thing that it is doing it and should I take the unit off or leave it work that area? It is helping with the pain right now.

Dr. Bruno's Response: In general, TENS not a good idea. There is one significant reason: polio survivors should listen to their bodies and stop before they have pain and treat the causes of pain, therefore, they should not use TENS units or medication to block out their body's telling them to stop doing what they're doing!

On the topic of Oxygen use vs. Bi-Pap (9/6/2015)

Original Post: What are your thoughts on using oxygen instead of bi-pap machines? Is anyone doing this? Because of "things" that occurred while I was hospitalized with Polio I am unable to have anything on my face.

Dr. Bruno's Response: Oxygen suppresses your brains urge to breathe but more importantly actually constricts blood vessels in your lungs effectively decreasing the size of your lungs. . Oxygen is no substitute for positive pressure ventilation with BiPAP or a volume ventilator.

John Bach's site is full of information on breathing and polio survivors. www.doctorbach.com