

# Polio Perspective

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## THE TEN COMMANDMENTS for POLIO SURVIVORS

*By Dr. Richard Bruno*

### 1) Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms.

However, polio survivors sometimes listen too much:

to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in you own head) saying you're lazy and that you must "use it or lose it."

Polio survivors need to listen to their own bodies, not to busy bodies.

### 2) Activity is not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors

with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

### 3) Brake, Don't Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240 percent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21 percent more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

### 4) A Crutch is Not a Crutch...

...and a brace is not a sign of failure or of "giving up." You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready." And 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?

### 5) Just Say "No" to drugs, unless...

Five studies have failed to find that any drug that treat PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medicine for a longer time after surgery or an injury (see 10 below).

### 6) Sleep Right All Night.

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such sleep apnea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. "Post polio fatigue" may be due to a treatable sleep disorder.

7) Some Polio Survivors Like it Hot.

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the polio virus. Actually, polio survivors' nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene (sold as GORTEX or THINSULATE) that holds in your body heat.

8) Breakfast Is the Most Important Meal of the Day.

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9) Do Unto Yourself as You Have Been Doing For Others.

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super-achievers, "the best and the brightest", doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time that you got something back for all you've done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing "disabled," by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

10) Make Doctors Cooperate Before They Operate.

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the polio virus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anaesthesiologist - long before you go under the knife. Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

The Golden Rule for Polio Survivors:

If anything causes fatigue, weakness, or pain, Don't Do It! (or do a lot less of it.)

. . . and . . .

The Golden Rule for Polio Survivors' Friends & Family:

See no evil, hear no evil... and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them to do. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

## **Diets high in animal protein may help prevent functional decline in elderly individuals** **From [www.sciencedaily.com](http://www.sciencedaily.com)**

A diet high in protein, particularly animal protein, may help elderly individuals maintain a higher level of physical, psychological, and social function according to a study published in the Journal of the American Geriatrics Society.

Due to increasing life expectancies in many countries, increasing numbers of elderly people are living with functional decline, such as declines in cognitive ability and activities of daily living. This can have profound effects on the health and well-being of older adults and their caregivers, as well as on health care resources.

Research suggests that as people age, their ability to absorb or process protein may decline. To compensate for this loss, protein requirements may increase with age. Megumi Tsubota-Utsugi, PhD, MPH, RD, of the National Institute of Health and Nutrition in Japan, and her colleagues in Tohoku University and Teikyo University, Japan, wondered whether protein intake might affect the functional capabilities of older adults.

They designed a study to investigate the relationship between protein intake and future decline in higher-level functional capacity in older community-dwelling adults in Japan. Their analysis included 1,007 individuals with an average age of 67.4 years who completed food questionnaires at the start of the study and seven years later. Participants were divided into four groups (quartiles) according to their intake levels of total, animal, and plant protein. Tests of higher-level functional capacity included social and intellectual aspects as well as measures related to activities of daily living.

Men in the highest quartile of animal protein intake had a 39 percent decreased chance of experiencing higher-level functional decline than those in the lowest quartile. These associations were not seen in women. No consistent association was observed between plant protein intake and future higher-level functional decline in either sex.

"Identifying nutritional factors that contribute to maintaining higher-level functional capacity is important for prevention of future deterioration of activities of daily living,"

said Dr. Tsubota-Utsugi. "Along with other modifiable health behaviors, a diet rich in protein may help older adults maintain their functional capacity."

**Story Source:**

The above story is based on [materials](#) provided by [Wiley](#). *Note: Materials may be edited for content and length.*

**Don't Give Me Your Attitude, I Have One of My Own**

*By Millie Malone Lill*

Raise your hand if you are tired of people making assumptions about you, your lifestyle, your financial status or your health, mental or physical, without truly even knowing you at all. That's what I thought. Most of us. OK, ALL of us!

I've been told that I was "far too retarded" (and those were the exact words, PC or not,) to raise a family. I raised three fine sons and took care of a husband whose health was never good besides. In spite of my seeming lack of gray matter, I managed a farm as well. I had help, of course, from those very sons and as much as could be managed from my husband, too. However, I was the one who bought and sold, wrote the checks, kept the books, and handled the budget.

On one occasion, I was in WalMart, looking for a poster one of the grandsons had requested as a birthday gift. I was in the store scooter and found there was no way to get to the display of posters. I knew one of the women working there and asked her why they'd put that display in such a difficult spot to reach. She looked me in the eye and told me that "people like you" were unlikely to be interested in such things.

Oh, that phrase really gets my goat. "People like you." Do you mean people who are short? People who have red hair? Perhaps you mean people who are not as rude as you are?? She was, of course, making assumptions based on the fact that I was not walking.

I've been told that I "look too good" to really need a wheelchair, that I need to "exercise off some of that fat" (this by a doctor, no less) and that I faked being able to walk so that I could smuggle my wheelchair into a senior housing complex that was already under the Fair Housing Act! Once I got over being angry about that last one, I stopped to wonder how one fakes being able to walk. I can walk, I don't have to fake it. I just can't walk very far or stand for very long without its causing me a lot of pain. Even so, anyone watching me walk would realize I don't do it well and certainly not gracefully.

I realize that PPS is an odd sort of thing. Other disabilities might be helped by working harder or exercising more, but PPS is made worse by this behavior. I have lived in this body for 72 years, and I know how it works and how it does not. No one else on the planet has this knowledge. Therefore, by informing myself, listening to my body and taking care of myself, I've made a very pleasant life without relying on strangers to advise me.

A casual acquaintance of many years once asked me why I always seem to be smiling and happy. The answer I gave him was that I live with me 24/7 and I don't want to live with a grouch. Actually, I usually am happy and that's why I smile. I have a lot for which to be grateful. I have friends who understand me, family who loves me, hobbies I enjoy, a decent living from the farm I worked so hard to keep.

What do we say to people who make these uncalled for assumptions? I don't know. Really, I just feel sad for them that they are so ignorant. I believe that living well is the best revenge. Also, I try to learn from the mistakes of others. It's unlikely I'll live long enough to make all of them myself, after all.

## Web Corner

A polio newsletter from Australia:

[http://www.postpolio.org.nz/\\_data/assets/pdf\\_file/0003/9507/PPSS\\_Newsletter\\_Aug09\\_v2\\_WebEdition.pdf](http://www.postpolio.org.nz/_data/assets/pdf_file/0003/9507/PPSS_Newsletter_Aug09_v2_WebEdition.pdf)

Radio program dealing with exercising with PPS:

<http://www.blogtalkradio.com/voice-aerobics/2014/03/14/the-role-of-exercise-in-post-polio-syndrome-limbs-speech-and-swallowing#.UzECzAayNLw.facebook>

Help in LA for PPS:

<http://www.examiner.com/article/help-la-for-post-polio-syndrome>

India proves why vaccines work:

<http://www.examiner.com/article/help-la-for-post-polio-syndrome>

Time for another "Ask Dr. Maynard"

[https://www.facebook.com/permalink.php?story\\_fbid=670651236329246&id=173414896052885](https://www.facebook.com/permalink.php?story_fbid=670651236329246&id=173414896052885)

Submission of Evidence in Disability Claims:

<https://www.federalregister.gov/articles/2014/02/20/2014-03426/submission-of-evidence-in-disability-claims>

"Talking Wheelchair Blues:"

<http://www.youtube.com/watch?v=6-wMFuAUW3Q&feature=youtu.be&hd=1>

Benevolence: From Guatamala to Goa on a Zimmer Frame (a free ebook written by a polio survivor)

<http://self.gutenberg.org/eBooks/WPLBN0002827615-Benevolence---From-Guatemala-to-Goa-On-a-Zimmer-Frame-by-West--Jim--William.aspx?&Trail=collection&Words>

Leicester Hosts Indoor Polio Games:

<http://www.pukaarnews.com/leicester-hosts-national-indoor-polio-games/9763/>

Listing of webinars hosted by the United Spinal Association:

<http://www.spinalcord.org/webinar-archive/>

## A Little Bit of Humor

### **The Perfect Husband**

Several men are in the locker room of a golf club. A cell phone on a bench rings and a man engages the hands free speaker function and begins to talk. Everyone else in the room stops to listen.

**Man:** "Hello."

**Woman:** "Honey, it's me. Are you at the club"?"

**Man:** "Yes."

**Woman:** "I am at the mall now and found this beautiful leather coat. It's only \$1,000. Is it okay if I buy it"?"

**Man:** "Sure, go ahead if you like it that much."

**Woman:** "I also stopped by the Mercedes dealership and saw the new 2014 models. I saw one that I really liked."

**Man:** "How much"?"

**Woman:** "\$90,000."

**Man:** "Okay, but for that price, I want it with all the options."

**Woman:** "Great! Oh, and one more thing. The house I wanted last year is back on the market. They're asking \$950,000."

**Man:** "Well, then go ahead and give them an offer of \$900,000. They will probably take it. If not, we can go the extra 50 thousand. It's really a pretty good price."

**Woman:** "Okay. I'll see you later! I love you so much!"

**Man:** "Bye! I love you, too."

The man hangs up. The other men in the locker room are staring at him in astonishment, mouths agape.

He smiles and asks, "Anyone know who this phone belongs to?"