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THE TEN COMMANDMENTS OF PPS

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After 15 years of searching, archaeologists from The Post-Polio Institute have unearthed the "commandments" for treating Post-Polio Sequelae (PPS) 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 busybodies.

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 medication 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 poliovirus. 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 poliovirus. 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 anesthesiologist - 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. 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.