

## **PAIN RELIEF:** Some tips from the collected wisdom of the Internet Polio Mail List – Tom Walters

Tom Walter is a polio survivor. Up until a few years ago, 30 years so on from recovering from Polio, he walked unaided with only a slight limp, working and living a normal life. He didn't even know any other people with Polio. He now has difficulty swallowing and breathing. He spends most of his days in a wheelchair or propped up in a bed. With his laptop computer he collects and dispenses advice and information on Post-Polio Syndrome. Tom, or TominCal as he is known by on the internet, is highly regarded and respected as a source of reliable information by the online Post-Polio community worldwide.

**NUMERO UNO –“Lifestyle Adjustment” – the “sine qua non” without which none of the other tips or aids seem to do much good. That means reducing physical exertion/activity AND mental stress to the level of one’s current capabilities.**

Dr. Jacqueline Perry, with over 40 years of experience at the Polio Clinic in Rancho Los Amigos medical Center in Downey, California, USA; says that we should exercise normal (if any) muscles normally but not do anything that causes PPS-affected muscles pain, weakness or fatigue that lasts more than 10 minutes. Assuming the person has been thoroughly checked for other conditions that could mimic PPS symptoms and be treated – and that any orthopedic anomalies that could be causing pain have been treated – here’s a partial list of some tips that PPSers have reported seem to work for them, alone or in combination:

1. Moist heat applied to the painful area
2. Light massage to the painful area.
3. Ice packs applied to the painful area.
4. Chiropractic or osteopathic “adjustment” of neck/back/joints.
5. Acupuncture; and electro-acupuncture to the ear lobe (auricular)
6. Herbal dietary supplements such as ginger, pycnogenol, cayenne pepper.
7. Treatment of sleeping difficulties, i.e., insufficient amount of Stage IV sleep.
8. Treatment of breathing difficulties, i.e., insufficient amount of oxygen and or too much carbon dioxide, especially during sleep.
9. Use of assistive and adaptive aids, as necessary, to reduce stress and strain to muscles and joints; assuring that all body parts that require it, e.g., neck, head, back, shoulders, are properly supported at all times.
10. For inflammation of muscles/joints – use of arthritis-type drugs: NSAIDS (Non steroidal Anti-Inflammatory Drugs). Over-the-counter types like Aspirin, Ketoprofen or prescription types like Relafen, Voltaren and Naprosyn.
11. For “nerve” pain – use of antidepressant prescription drugs –
  - a. Elavil (amitriptyline) – an anti-depressant of the tricyclic type – is the first choice in drug therapy by some PPS specialist docs for those with PPS pain AND trouble sleeping, at dosages less than would be used for clinical depression. But a lot of us don’t tolerate it well.
  - b. And for those (and also those who DON’T have sleeping problems), one of the SRUB class of anti-depressants (Serotonin ReUptake Blockers) such as Zoloft or Paxil – also in smaller doses that would be used for clinical depression – may be of help.
  - c. A more recent addition to the medications that help with Nerve pain is Neurontin – generic name of Gabapentin.
12. Occasional and/or careful use of muscle relaxants such as Quinine, Flexeril, Methocarbamol or Skelaxin. Please be sure that you do not have breathing or respiratory issues that would be compromised by these drugs.
13. Hormone Replacement Therapy, especially for post-menopausal, post-hysterectomy women and others with lower than normal levels of estrogen, testosterone, thyroid, DHEA, melatonin.

**PAIN RELIEF**  
**SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS**  
 Changes and Strategies report by people, aging with Childhood onset Polio

<b>PRIMARY CHANGES</b>	<b>CONSEQUENCES</b>	<b>STRATEGIES</b>
Physical Fatigue	Decreased time on projects Unable to multi-task	Rest Breaks Planning and Organization
Mental Fatigue	Mistakes made when on task too long	Frequent breaks Postpone important decisions
Pain	Stopped and altered activities	Massage, exercise, medications, and assist devices
Balance Problems	Falls – Fear of Falls	Assistive devices Walking on even and Textured flooring Planning and knowing layout of surroundings
Decreased Dexterity	Do fewer complex activities that require full range of motion	Assistive devices for reach Asking for Assistance Changing grooming practices Change clothing types Portable assist devices
Decreased Muscular	Less Lifting Decreased ability to clear lungs with diaphragm Decreased ability to push self in chair or pull self up from toilet	Ask for assistance Pneumonia shot Breathing aids Portable devices, such as toilet seats and ramps
Temperature Shifts	Decreased desire to go out	Layering with multiple clothes Heating Pads
<b>SECONDARY CHANGES</b>	<b>CONSEQUENCES</b>	<b>STRATEGIES</b>
Obesity	Type 2 diabetes Further decreased in strength Further change in clothing style Ulcers	Surgeries Exercise Resignation
Altered Appearance	Decreased desire to go out in public Decreased self-esteem	Cut hair short but stylish Dye hair Ask for Assistance
Fractures	Hospitalizations, surgeries and further mobility impairment	Hire Assistance
Fewer sexual experiences	Marital conflict	Sexual banter or other means of intimacy
Isolation	Fewer people to provide assistance when needed	Computer contact via Internet Telephone Conversations
Side effects from Medications	Falls, weakness, balance disturbances	Change Medications and/or use alternative therapies
Emotional and Psychological disturbances	Crying, anxiety, and nervousness	Decrease mental stimuli

*Strategies for Living Well June 2-4, 2005 St. Louis, Missouri*  
*Post-Polio Health International including International Ventilator Users [www.post-polio.org](http://www.post-polio.org)*