Now called
Post-Polio Health

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Use of Medication in People with Post-Polio Syndrome

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Until we better understand the causes of post-polio syndrome, we will have no curative medication. At best, we can use medication to treat the symptoms and to improve the quality of life, and we can avoid using medication that could make the symptoms worse. Certain other diseases (elevated blood cholesterol levels, high blood pressure, heart disease, and cancers) require use of medications with side effects that can exacerbate symptoms of post-polio syndrome. These should be used, but with careful monitoring of the polio survivor's functioning.

Symptomatic Medication

The three primary symptoms that we can treat with medication are weakness of muscle, fatigue (individual muscle and generalized), and pain, i.e., post-polio pain, overuse pain, bio-mechanical pain, and bone pain (Gawne, AC, 1995).

Drugs to reverse muscular atrophy or to improve muscle strength by stimulating motor nerve endings to reconnect with muscle fibers *(nerve growth factors)* are all still experimental. They are currently being tested for use with other motor nerve diseases. Only insulin-like growth factor type 1 (IGF-1), also known as myotrophin or somatomedin-C, has been tested in people with post-polio syndrome (Miller, RG, 1997). (See chart on page 3.) It brought no change in strength or fatiguability, but did improve recovery from fatigue after exercise. Human growth hormone has been given to increase a person's natural level of IGF-1, but showed little or no improvement in strength (Gupta, KI, 1994).

Another approach has been to develop and test drugs that would protect the nerve-muscle connection from new damage in the first place *(neuro-protective agents).* Again, several have been studied in other diseases, but only selegiline has been tested in post-polio syndrome, bringing some improvement in symptoms but no clear stabilization of the disease (Bamford, CR, 1993). Although many people use over-the-counter antioxidant preparations of various types, these have never been formally tested to prove any ability to slow down the changes of post-polio syndrome.

Anabolic steroids, often used by body builders to improve muscle bulk and power, have been tried by polio survivors and other persons with neuromuscular diseases, but *The Medical Letter on Drugs and Therapeutics* reports the side effects (risk of prostate cancer in men, masculinization in women) greatly outweigh the potential benefits. *Metabolic stimulants* (L-carnitine*, L-acylcarnitine, co-enzyme Q), used to improve the ability of muscle to make energy and possibly reduce fatigue and improve strength, have also been tried by polio survivors, but have been associated with rare allergic reactions and insomnia (Lehmann, T, 1994; Nibbett, J, 1996).

Specific *anti-fatigue drugs* can act either in the brain itself (on pathways controlled by dopamine and noradrenaline) or by improving communication at the nerve-muscle connection. These are, respectively, central and peripheral agents. Centrally-acting anti-fatigue medications include amantadine, bromocriptine, selegiline, pemoline, ephedrine, and certain antidepressants (selective serotonin re-uptake inhibitors, which may also have nonadrenaline activity). All have been tested in other fatiguing neurologic illnesses, but only the first three have been studied in post-polio syndrome. Amantadine provided no reduction in fatigue (Stein, DP, 1995), but bromocriptine (Bruno, RL, 1996) and selegiline (Bamford, CR, 1993) did. Several studies have been done using pyridostigmine, a peripherally-acting drug, (Trojan, DA, 1993, 1995; Seizert, BP, 1994; Trojan, DA, 1997) that reflected variable effects on fatigue, possible mild improvement in strength in very weak muscles, and notable side effects (primarily gastrointestinal).

When contemplating the use of anti-fatigue drugs, we first treat any concomitant problems (other medical or neurological illnesses, sleep disorders, depression) that could be adding to fatigue.

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When rehabilitation techniques have not given adequate *pain relief* and medications must be used, we determine where the pain is coming from before choosing the most specific treatment agents. In our experience, for true post-polio muscle pain, centrally acting, non-narcotic drugs work best (serotonin-stimulating medications, e.g., tricyclic antidepressants, clonazepam, tramadol; central nerve relaxants, e.g., baclofen, tizanidine; nerve stabilizers, e.g., anticonvulsant drugs like carbamazepine or gabapentin).

Fortunately, we have no drug for overuse pain. If we did, using it would be like taking the batteries out of a smoke detector because it is noisy at night. This pain makes polio survivors aware that they are overdoing and need to cut back.

Biomechanical pain resistant to non-drug strategies may respond to short-term use of non-steroidal anti-inflammatory drugs (NSAIDs). Some survivors may experience the side effect of gastrointestinal problems.

Joint-related pain may require cautious long-term anti-inflammatory therapy. When a true analgesic is required, whether it is as simple as acetaminophen or as strong as a narcotic, it should be taken in moderate amounts and on a schedule, not just when the pain is so severe that a higher dose is necessary. If taken together, mild antihistamines or anti-anxiety medication may make painkillers work better and at a lower dose, but do have their own side effects.

Acupuncture, electro-acupuncture, acupressure massage, and possibly magnetic therapy may work on painful muscle areas along the same pathways as narcotics, and all have been tried in post-polio syndrome. Pain caused by fibromyalgia may respond to low, bedtime doses of amitriptyline (Trojan, DA, 1994).

Cautions about Medications

Many drugs may have drowsiness as a side effect or may increase fatigue within the general population. (Always check the label or ask the pharmacist or physician.) These include central nervous system (brain) depressants, e.g., narcotics, sedatives, tranquilizers, sleeping pills, and alcohol; antihistamines; antidepressants; and anti-anxiety agents. Polio survivors who take these medications may experience an increase in polio-related weakness and fatigue.

Diuretics (water pills) and laxatives may deplete the body of essential minerals required by nerves and muscles for normal functioning. Many other drugs (antibiotics, chemotherapy agents, even megadoses of some vitamins, e.g., B_6) can contribute to nerve damage. Muscle relaxants and drugs similar to them in chemical structure (quinine, quinidine, procainamide), as well as other medications used for heart or blood pressure problems (beta-blockers, calcium channel blockers), may add to polio-related weakness and fatigue.

Anecdotal evidence suggests that cholesterol-lowering medications of the "statin" family may also increase polio-related weakness and fatigue. Polio survivors, particularly those with a lesser muscle mass, have reported fewer and less dramatic side effects from some medications when taking a lower dose.

Polio survivors and their physicians should scrutinize all medications – current and newly added – used to treat various medical problems to be assured that related conditions, such as fibromyalgia, elevated cholesterol, high blood pressure, etc., are appropriately treated, but with minimal effect on polio-related symptoms. ■

*A placebo-controlled study, as yet unpublished, recently done in Germany showed no significant difference between placebo and L-carnitine.

Post-polio syndrome is a constellation of new symptoms (fatigue, weakness, pain, cold intolerance, muscle atrophy, or new problems with activities of daily living), occurring in survivors of definitively (by history, exam, or electrical studies) proven acute poliomyelitis, after a period of at least 15 years of stable recovery and performance, and in the absence of any other medical or neurological condition. It is felt to result from the weakening and loss of previously recovered lower motor neuron connections to muscle, possibly due to aging, greater fragility of the recovered nerves, or immune system dysregulation. Onset can be insidious, progression is usually slow, and treatment is most successful with rehabilitation strategies.

– Susan Perlman, MD

Susan Perlman, MD is Associate Clinical Professor of Neurology and Director of the Post-polio Clinic at UCLA. Since 1988, the clinic has evaluated and treated 600 polio survivors, with an approach combining neurological assessment, neurorehabilitation techniques, medication intervention, and consultation with associates in orthopedics, medicine, sleep disorders, psychology, and alternative (complementary) medicine. The clinic coordinates with the dedicated support groups in southern California and offers educational outreach to the health care community.

Table. Pharmacology of Post-Polio Syndrome: Recent Trials

Drug	Category	Type of Trial	N	Results in PPS
Amantadine	Anti-viral	Randomized, placebo-controlled trial	25	No significant improvement in fatigue[1]
Prednisone (high-dose)	Steroid, anti-inflammatory	Randomized, placebo-controlled trial	17	No significant improvement in strength or fatigue[2]
Human growth hormone	Hormone	Open trial	5	Little or no improvement in muscle strength[3]
Bromocriptine	Dopamine receptor agonist	Placebo-controlled, cross-over trial	5	Improvement in fatigue symptoms in 3 patients[4]
Selegiline	Neuro-protective agent	Case studies	2	Improvement in PPS symptoms[5]
Pyridostigmine*	Anti-cholinesterase	Open trials	17, 27	Improvement in fatigue[6,7]
		Placebo-controlled, cross-over trial	27	Improvement in fatigue, strength[8]
Insulin-like growth factor 1 (IGF-1)	Growth factor	Randomized placebo-controlled trial	22	Improvement in recovery after exercise, change in strength, fatiguability[9]

[1]Stein DP et al. A double-blind, placebo-controlled trial of amantadine for the treatment of fatigue in patients with the post-polio syndrome. *Ann NY Acad Sci* 1995;753:296-302.

[2]Dinsmore S et al. A double-blind, placebo-controlled trial of high-dose prednisone for the treatment of post-poliomyelitis syndrome. *Ann NY Acad Sci* 1995;753:303-313.

[3]Gupta KL et al. Human growth hormone effect on serum IGF-1 and muscle function in poliomyelitis survivors. *Arch Phys Med Rehabil* 1994;75:889-894.

[4]Bruno RL et al. Bromocriptine in the treatment of post-polio fatigue. *Am J Phy Med Rehabil* 1996;75:340-347.

[5]Bamford CR et al. Postpolio syndrome response to deprenyl (selegiline). *Int J Neurosci* 1993;71: 183-188.

[6]Trojan DA et al. Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue. *J Neurol Sci* 1993;114:170-177.

[7]Trojan DA, Cashman NR. An open trial of pyridostigmine in post-poliomyelitis syndrome. *Can J Neurol Sci* 1995;22:223-227.

[8]Seizert BP et al. Pyridostigmine effect on strength, endurance, and fatigue in post-polio patients (Abstract). *Arch Phys Med Rehabil* 1994;75:1049.

[9]Miller RG et al. The effect of recombinant insulin-like growth factor 1 upon exercise-induced fatigue and recovery in patients with post polio syndrome (Abstract). *Neurology* 1997 (in press).

*An article detailing the results of the North American Post-Poliomyelitis Pyridostigmine Study (NAPPS) has been submitted for publication.

Post-Polio Bibliography

◆ Wilson, D. (1998). A crippling fear: experiencing polio in the era of FDR. *Bulletin of the History of Medicine*, 72, 464-495.

Polio survivor and professor at Muhlenberg College, Allentown, PA (Pennsylvania), explores published polio narratives, transcriptions of oral history interviews, and letters written to President Roosevelt during the polio epidemics between 1930 and 1945.

This exploration beyond the public polio image created in the popular press and medical writings reveals a more complex picture of the polio experience than encompassed in previous accounts.

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