



Tom Walter's "Letter from California"

COMING BACK FROM HELL

OR

Something Worse than PPS?

The past six months or so I've not been able to keep up with answering correspondence, E-mails and telephone calls; visiting friends and relatives; sending out appropriate greeting cards on a timely basis; putting together pages for the local support group newsletter; or just about anything else I've been doing during the past couple years of disability from Post Polio Syndrome.

About the only thing I've been able to continue regularly is the Tuesday night [self-help support chat](#) we have on America Online. And I'm so far behind on everything else I won't ever catch up.

Around Thanksgiving last year, I came down with a terrible head cold that lasted about two months and took me out of the usual round of end-of-the-year holiday activities and festivities. Then the day after Valentine's, 1998, I started having new pains in my shoulders. I remember buying a discounted plant late in the day and re-potting it when I got home. So I figured I may have "overdone" it.

But after three weeks of babying and protecting my shoulders, the pain and stiffness were intensifying and spreading to my neck and upper arms -- pain much more excruciating than I had experienced so far from PPS, even though I was now consuming massive quantities of narcotic pain medications: pain that prevented me from rolling over in or sleeping in a bed and allowed me little uninterrupted sleep in my rocker-recliner, pain that kept me from driving my van.

I began wondering about torn rotator cuffs, pinched nerves, brain or spinal cord tumors. Or had I slipped to a new, lower level of functioning because of rapidly-advancing PPS? I started using the local County wheelchair-lift equipped bus system and the handicapped "Dial-A-Ride," had a man in to help out with routine chores one day a week (in addition to the weekly gardener and bi-weekly cleaning ladies) and signed up for delivery of "Meals on Wheels."

Time to seek medical evaluation. My Primary Care Physician ordered x-rays of the neck and shoulders which were unremarkable. Then how about some blood tests? Most everything "within normal limits" except for the "sed rate." An elevated Erythrocyte Sedimentation Rate (ESR) can indicate inflammation in the body, but not the cause or location of that inflammation.

By the time I saw the Orthopedist who's been treating my PPS two months after this started, pain and stiffness had spread to my lower back and "better" right hip and thigh. It seemed that my entire body was involved, except for my "worse," atrophied left leg. But he didn't think this new additional pain and stiffness was related to PPS.

More blood tests to eliminate autoimmune and connective tissue disorders. The pattern and extent of pain, weakness and stiffness and the elevated "sed rate" are characteristic of Polymyalgia Rheumatica (PMR), a rare form of arthritis usually seen in 70-year-old-plus women and also known as Anarthritic Syndrome or Arthritic Rheumatoid Disease that involves an inflammation of the muscles or joints or arteries.

Now three months had gone by and I see a Rheumatologist. He confirms the diagnosis and starts me on a course of oral Prednisone.

Prednisone is a steroid that can have a lot of negative side effects, including thinning of the skin and bones, suppression of the immune system, muscle weakness and lethargy, mood swings, weight gain and fluid retention and more. But its the only known effective treatment for Polymyalgia Rheumatica. The course of treatment usually lasts six months to two years when the "sed rate" returns to normal and the pain and stiffness subside.

(In the May 15, 1995, Annals of the New York Academy of Sciences, Dr. Dalakas reported his double-blind, placebo-controlled trial of high-dose Prednisone for the treatment of PPS conducted at the National Institutes of Health in Bethesda MD. No further studies of the drug are planned in PPS because patients exhibited substantial undesirable side effects and the lack of significant efficacy to show any benefit for general fatigue or muscle fatigue, although a few patients did feel it had helped.)

The past week I've been having some "ups and downs" in terms of energy, fatigue and pain, the drug treatment has me back on the road to recovery, with renewed high hopes of returning eventually to function at or near levels before the onset of this rare disorder.

And I'll also be starting soon one of the newer drugs for osteoporosis prevention and treatment (Fosamax tablets or Miacalcin Nasal Spray).

The cause of Polymyalgia Rheumatica is unknown, but may be a virus or genetic. It does not seem to be related to Polio or PPS. In a casual conversation about this, Dr. Susan Perlman of UCLA recalled only about two cases in 500 polio patients she's seen over the years in the Clinic there. And Dr. Halstead noted that he probably sees less than one case a year among his patients at the National Rehabilitation Hospital in D.C.

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