



A Letter to a Polio Survivor

**The following is a genuine letter which has been depersonalised.
Publication at the suggestion and with the permission of Professor Richard L.
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POST-POLIO REHABILITATION AND RESEARCH SERVICE Office of the Director
21 February 1997

Dear Polio Survivor:

1) You were asked if you have evidence that you in fact had polio.

[Fill in here your past history of Polio]

2) You have been told that one had to have significant damage from the polio and muscle atrophy to have PPS.

Neither the severity of the original polio infection nor muscle atrophy, either due to the original polio or late-onset atrophy - are required for the diagnosis nor are predictors of PPS. The postmortem studies of Professor David Bodian of Johns Hopkins University in the 1940's showed that anyone who had paralytic polio lost on average 50% of their anterior horn cells but required the death more than 60% to demonstrate any paralysis (Bodian D. Histopathological basis of clinical findings in poliomyelitis. *American Journal of Medicine*, 1949; 6: 563-578.)

However, Bodian also found that at least 90% of all anterior horn cells were in some way affected during the polio infection (Bodian D. 1947. Poliomyelitis: Neuropathologic observations in relation to motor symptoms. *Journal of the American Medical*

Association, 1947, 134:1148-1154).

With regard to the prediction of PPS, our research and that of other investigations (see Klingman, et al. Functional Recovery: A major risk factor for the development of PPS. *American Journal of Physical Medicine and Rehabilitation*, 1988, 45:645-647) show that it is the degree of original paralysis plus the degree of recovery that predicts PPS. Klingman showed that 79% of the variance of PPS symptoms "could be accounted for by recovery alone."

Our research has also shown that physical overexertion is also a primary factor in triggering PPS in 96% of subjects in the first American National Survey of Polio Survivors (Bruno RL, Frick NM: [Stress and "type A" behavior as precipitants of post-polio sequelae](#). In: Halstead LS, Wiechers DO (eds): *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains, NY, March of Dimes, 1987, pp. 145-155).

3) You have been told you must use your limbs and that, if you did not, then the muscles would wither away.

This advice is particularly inscrutable. All of the world's medical research and clinical literature on the treatment of PPS shows that persisting in physical exertion in the face of new symptoms, and especially the prescription of exercise, continue the downward progression of PPS.

The recommendations for energy conservation and assistive device use provided you are just right (see [Young GR. Energy conservation, occupational therapy and the treatment of post-polio sequelae. *Orthopedics*, 1991; 14:1233-1239](#)). A two-year follow-up study of patients treated by the Roosevelt Institute at Warm Springs showed that patients who refuse to implement such suggestion have pain and fatigue increase and lose more than 2% of muscle strength per year ([Peach PE, Olejnik S. Effect of treatment and non-compliance on post-polio sequelae. *Orthopedics*, 1991; 13:1199-1203](#)). Patients who implemented energy conservation and assistive device use actually gained muscle strength over time.

Our just-completed follow-up study of patients treated by the Kessler Post-Polio Service since 1990 shows a 76% increase in muscle weakness over 16 months in patients who refuse to implement energy conservation and assistive device use. Patients who do implement these suggestion report a 21% decrease in muscle weakness.

4) You have been told that PPS is all conjecture and that PPS is not a problem in Lincolnshire.

I would have readily agreed that PPS was all conjecture in 1983. But after four international symposia and thirteen years of research published in journals including *Neurology*, *the Archives of Physical Medicine and Rehabilitation*, *the American Journal of Physical Medicine and Rehabilitation*, *the Journal of Rehabilitation*, *the Journal of the American Medical Association*, and *the Annals of the New York Academy of Science*, there is no longer any conjecture about the reality of PPS.

With regard to the prevalence of PPS in the U.K., 74,280 cases of polio had been reported to the U.K. Communicable Disease Surveillance Centre between 1912 and 1961. As in the United States, the ratio of polio cases to actual notification of the C.D.S.C. was quite low before the large epidemics of the late 1940's, your government describing notification as "far from complete."

The cases of polio reported to our Centers for Disease Control was 480,000 during the same period, with notification also being described as unreliable since U.S. physicians were not required to notify the C.D.C. of polio cases until 1952. It is not surprising then that 1987 U.S. Department of Public Health National Health Interview Survey calculated that there were 1.63 million Americans alive today who had had polio. It is likely that the actual number of living survivors of polio in the U.K. is closer to 250,000.

With regard to the prevalence of PPS, the recent survey of the membership of the British Polio Fellowship found the incidence of PPS to be 77%. Therefore, between 57,000 and 192,000 British polio survivors are experiencing the same symptoms that you report.

I cannot encourage you strongly enough to be physically examined and to immediately implement all of the recommendations made by your Doctor and your occupational therapist and any other ideas of which you can conceive to save your remaining polio damaged motor neurons.

I hope I have answered your questions and concerns. I encourage you to obtain and show the articles I have referenced herein to your physicians. Please contact me if you, your physicians or therapists have further questions.

Yours truly,
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and
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