



Terminology

by Tom Walter

Tom Walter is a Polio Survivor. Up until a few years ago, 30 years or 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 and spends most of his days in a wheelchair or propped up in bed. With his laptop computer he collects and dispenses advice and information on post-polio syndrome. Tom, or TominCal as he is known by his email name, is highly regarded and respected as a source of reliable information by the online post-polio community worldwide.

LincsPPN Web Administration.

Different clinics, doctors, organizations use terms differently, with different meanings or interchangeably, to describe our PPS. And I don't believe there is any general agreement on their meaning. Here's some samples.

Not saying it's right or wrong, but the Social Security Administration calls it the "Late Effects of Polio" and states in its Medical Evaluation Manual:

"For the purposes of evaluation under the disability programs, the late effects of polio refer to new symptoms and neuromuscular manifestations which result in new functional loss in an individual with a prior history of acute polio. This functional loss typically occurs after a long period (more than 10 years and generally 20-40 years) of stability."

Dr. Jacquelin Perry gave the following definition at the 1994 GINI Conference -- after over 40 years experience at the Rancho Los Amigos Polio Clinic in Downey CA --

"The term 'late effects of polio' is the umbrella over three subdivisions...

"...First are the asymptomatic post-polio individuals who have a known history of polio but who are not having troubles now...

"...The second group has symptoms which indicate the lifestyle demands now exceed their muscles' ability to meet those demands. The symptoms of pain, fatigue, and new weakness are signs of overuse with a penalty...

"...The third group, which we often overlook, is the polio survivor with joint degeneration problems. It is just plain wear and tear, either from substitutive posture used to replace inadequate muscles, or the impact of loading a joint instead of letting it yield on the muscles."

At the same conference, Dr. Lauro Halstead, head of SCI and PPS services at the National Rehab Hospital in DC said:

"We do not have enough information, insight, or wisdom to separate specific definitions except for clinical use.

"The three major diagnostic terms -- the late effects of polio, post-polio syndrome and post-polio muscular atrophy -- can be described by imagining three concentric circles. A large outer circle labeled the late effects of polio represents a grab bag. Anyone who has serious involvement with

a neuromuscular disease, and it does not have to be polio, will experience a variety of problems, if they live long enough.

"The late effects of polio refers to a group of symptoms and signs which people who had polio many years ago now experience and include weakness, fatigue, muscle pain, joint pain, decreased endurance and new atrophy. They also include increased weight gain, osteoporosis, increased risk of fractures, scoliosis, increase in pulmonary problems, sleep difficulties, and psychological problems.

"People can experience a whole list of problems that are in the big circle as a result of having had polio, but they do not have post-polio syndrome.

"Inside the big circle is a smaller circle labeled post-polio syndrome. More narrowly defined, a diagnosis of post-polio syndrome requires the presence of new neurogenic weakness. . . . Post-polio syndrome is a neurologic disease which occurs as a result of having had an invasion of the polio virus to part of the nervous system many years earlier...

"...The smallest and most inner circle is post-polio muscular atrophy and is reasonably straightforward. It is post-polio syndrome in someone with new muscle atrophy.

"Another better term that might be used for these last two diagnoses is post-polio motor neuron disease which focuses on the motor neuron as the primary source of pathology."

And at that conference, Dr. Neil Cashman co-head of the Polio Clinic at the Montreal Neurological Institute commented:

"Today there is no consensus, no position paper, no diagnostic test, no agreed-upon criteria about this syndrome, so there will be differences of opinion and some overlap...

"...There is a running controversy in the medical literature of 'lumpers' and 'splitters.' Some authorities like to put diseases together under certain rubrics, and others like to break off certain diseases. My opinion is that it is too early to split sub-syndromes off the post-polio syndrome.

"My conservatism, in part, is based on work with people who had post-polio muscular atrophy. People with atrophy were just as likely to have pain and fatigue as people without new atrophy. There is not enough data to make a distinction and say this is merely musculoskeletal; that is neurogenic. They act differently and they are treated differently.

"The original meaning of the word 'syndrome' comes from the Greek -- 'running together.' These symptoms present in polio persons time after time, and the symptoms really do run together. There is something going on and, in my opinion, it is too early to dogmatize sub-groups.

"The safest term, to date, is post-polio syndrome, and the safest definition of the post-polio syndrome is a new clinical syndrome of pain, weakness and fatigue in individuals who recovered from acute paralytic poliomyelitis."

*Tom Walter
22nd March 1997*

LincsPPN Editorial Footnotes.

Terminology.

One other term requires mentioning, that being Post-Polio Sequelae. The following extract from a 1986 article¹ explains its usage.

The new symptoms reported by persons who had polio have been given a variety of names by the popular press, including "Post-Polio Syndrome " and Post-Poliomyelitis Progressive Muscular Atrophy (PPMA). The initial magazine articles that named the new symptoms also

proffered their probable cause. It was suggested that the polio virus, lying dormant in the spinal cord for thirty years, had become reactivated and was giving people polio for a second time. It was also suggested that new weakness was the result of "some kind of amyotrophic lateral sclerosis." These two suggested etiologies are now regarded as incorrect. The researchers and clinicians who gathered at Warm Springs, Georgia for the First International Symposium on the Late Effects of Poliomyelitis in May, 1984 rejected both explanations because neither has been supported by empirical evidence. The name "Post-Polio Syndrome" was rejected since most persons report some but not all of the five major symptoms listed [unaccustomed fatigue, so severe in some individuals that they must lie down to rest in the middle of the day - a phenomenon called the "Polio Wall"; new joint and muscle pain; new weakness in muscles affected and in those apparently unaffected by the polio; new respiratory difficulties in those who had bulbar or upper spinal polio that require some to return to using a respirator; cold intolerance, where exposure to even mild cold temperatures results in noticeable muscle weakness, marked coldness and discoloration of the limbs and burning pain - symptoms that increase with aging]. The term Post-Poliomyelitis Progressive Muscular Atrophy (PPMA) was also rejected as a general descriptor of the new symptoms since the over-whelming majority of persons reporting new symptoms are not experiencing progressive muscular atrophy. The Post-Polio Task Force, meeting again in Boston in October, 1984, adopted the term Post-Polio Sequelae as the general descriptor of the new symptoms.

¹ Post-Polio Sequelae: Physiological and Psychological Overview by Nancy M. Frick, M. Div. and Richard L. Bruno, Ph.D. [[Lincolnshire Library Full Text](#)]

Definitions.

For several decades there has been a tendency to require a history of **paralytic** polio before any diagnosis of PPS will be considered. Such a pre-requisite is **not** supported by medical papers written in the 1950's and earlier that report evidence of a level of neuronal damage by the polio virus that does not present any clinical signs of paralysis at the time of infection. Hence, a history of **non-paralytic** polio **does not** preclude new PPS symptoms or a diagnosis of PPS when all other possible conditions have been excluded.

For a detailed explanation read *Non-Paralytic Polio and PPS* by Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology. A Lincolnshire Post-Polio Library publication. [[Lincolnshire Library Full Text](#)]

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