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Question: *I've asked my doctors in the past about PPS, and they indicate that at my age – 65 – it is highly unlikely that I could develop PPS since it has been so many years since I contracted polio. Do you have any statistics on PPS occurring 60 years after having polio?*

A: I am unaware of any statistics on the average age when a diagnosis of PPS is made using the 2001 March of Dimes criteria for this diagnosis. Many studies have described the age at first onset of “symptoms” and generally this has been 25 to 35 years after the (acute) polio.

The average interval of years since polio to onset of new symptoms has been reported as longer for the symptom of new weakness in previously unaffected muscles (42.6 years) compared to previously affected muscles (34.4 years). But among polio survivors not hospitalized at the time of polio onset, the average age of new weakness was 59.3, ± 4.7 years, and 55.8, ± 10 years, for muscles previously unaffected or affected respectively (see Halstead et al, in Late Effects of Poliomyelitis, Symposia Foundation, 1985). Therefore having the onset of PPS symptoms 60 years after polio certainly can occur.

Probably most medical experts on PPS believe some new weakness is inevitable among aging polio survivors. What may be unusual is for someone to reach age 80 or more without already recognizing some new weakness AND without another non-polio-related health condition that produces new weakness. The three greatest risk factors for developing PPS are severe initial involvement, greatest amount

of recovery and chronological age (older) – none of which can be altered. This is why education about EARLY recognition of symptoms and prompt management of them (including rehabilitation interventions) are the best way to slow progression and maintain functional abilities needed for a high quality of life.

Question: *My physician retired, and my new primary care doctor is “re-evaluating” everything. I am nervous because he is questioning my medications, and I am not sure he understands my history. Can you help me understand his approach and offer assuring advice as he and I get to know each other? I am especially concerned about my new doctor’s making me reduce the pain medications I need.*

A: For a new primary care physician to want to “re-evaluate everything” about your health is a good thing because it means he/she cares enough about you to try and understand all your past and current medical problems and to gain a sufficient level of certainty that current conditions and symptoms are being optimally managed. I would encourage you to look forward to a re-evaluation as a chance for you also to review and possibly learn more about your own conditions – and to possibly teach another physician about the late effects of polio.

Reviewing all your medications taken with any regularity, especially those

requiring the new doctor to authorize by prescription, is an essential part of this review. Medication use can be considered in four general categories: 1) *Required*, as necessary to treat a serious (potentially life-threatening) condition; 2) *Recommended*, as probably helpful to treat a serious condition; 3) *Useful*, to prevent recurrent symptoms (non-life-threatening); and 4) *Useful*, to treat/reduce episodic symptoms (written as *prn – pro re nata* – meaning use as needed).

Patients are frequently anxious about having unfamiliar new medical providers change medication use in the last two categories, and yet these are the categories where there is the most misuse of medications and the greatest potential to make beneficial changes. Frequently, medications for a non-serious condition, such as persistent heartburn, are continued for years although the condition is not usually a lifelong, permanent or persistent problem and there are many lifestyle changes possible to prevent the symptoms.

Your concerns about changes in pain medication prescriptions is understandable since only you experience your pain – it can not be seen or measured by others. Nevertheless, regular pain medication use does lead to physical and psychological dependence and sometimes addiction. Pain medications also all have some negative health side effects, and it is important that they are regularly reviewed – by both familiar and new providers.

Post-polio pain problems are often complex, greatly varied in causation

and rarely life-threatening. They can be treated, managed and prevented in many different ways and, therefore, are ideal for periodic review in the hope of finding new, more-effective and/or safer methods. In my opinion it is almost always preferable for a person's long-term health to use non-pharmacological methods of pain control and especially to avoid the use of opioids, the most habituating pain medications, for non-malignant pain problems. Please try your best to embrace your new physician's re-evaluation for what may be "new thinking" about your "old problems" that may lead to better solutions. ▲

SEND YOUR QUESTIONS
FOR DR. MAYNARD TO
INFO@POST-POLIO.ORG.

Letter to the Editor

I just want to thank you for the work you do to help polio survivors. I was stricken with polio in 1943 at age 3. I started in an iron lung, and with surgeries and God's help, I was able to walk with braces and then on my own.

I am now 70 years old. I have survived cancer, blood clots, weakened and failed muscles. Along with most polio survivors, we never say "I can't." When something quits, we say "OK" and find another way to continue on.

I so enjoy reading others' stories and solutions and wish I could find doctors as informed as those who contribute to the newsletters. My doctors seem to think it's unusual to find a 70-year-old polio survivor.

I wish I could send more support, but a yearly subscription is all I can do, and I'm thankful to get so much information for so little. May God bless you all for what you do to help keep us informed.

Sue McAlexander

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