

LEADERSHIP

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QUESTION: “My physician seems to have little knowledge of potential polio problems. Should I be worried? What are my options?”

ANSWER: The good news is that we are way beyond the days when polio survivors took their complaints to a puzzled doctor who felt his only recourse was to refer us to shrinks for what he thought were our imaginary ailments. Today’s medical community is aware of post-polio syndrome. Most doctors now see PPS as a legitimate medical problem. That’s one hurdle behind us.

Are all physicians prepared to treat the many manifestations and nuances of this condition? Of course not—no more so than they were when polio came our way in the first place. There’s nothing new about the fact that medical science seems woefully inadequate to individuals who pose perplexing challenges beyond a doctor’s knowledge. I’ll bet it seems that way to doctors, as well. There’s plenty of frustration to go around.

Polio support groups can help.

Why not start by working together to figure out sensible ways to think about the situation? We have all known survivors who, amazingly, seem devoted to whining about yesterday, rather than considering today’s possibilities. Dynamic groups discuss healthy ways to bring issues into focus. Seeking solutions is always better than dwelling endlessly on the problem.

Groups can explore creating better partnerships with doctors. For our part, we must give up expecting the quick fix of a pill for every malady. We must learn to work together with our doctors. If physicians and patients, together, approach this alliance with open minds and the willingness to listen, we will both learn new things. It’s not a matter of magic—if we expect answers beyond what we now receive, then we must participate in the search for our wellness.

Herein lies the opportunity for a most productive meeting. Members might talk their way to truly helpful revelations. They could also devise an “office visit list”—some DOs and DON’Ts to propel individuals way beyond the usual. Perceptive groups will come up with lists much keener than the short one below—let these few simple samples serve as inspiration:

- DO write a list of personal concerns and take it to discuss with the doc.
- DO present issues succinctly and clearly.
- DO ask pertinent questions.
- DON’T be shrill and demanding—or a wilted petunia, either.
- DON’T waste the doctor’s time.
- DON’T assume patients know nothing (or everything)—and doctors know everything (or nothing).

- Another good activity—Groups can answer these questions, as well:
 - How can we successfully vie for the attention of a physician who is overscheduled and underinformed?
 - How can we improve our own behavior as patient-physician partners?
 - How should we judge our expectations—is what we expect reasonable?
 - How do we ready ourselves factually to carry the post-polio message?
 - How do members respond to the statement “If we want better doctors, we must become better patients”?
 - How accurate is it to believe that younger doctors know little about polio, whereas older ones are well-informed?
 - How do we encourage members to tell doctors they had polio and to be persistent in asking if their difficulties could be connected to PPS?

Interactive meetings provide a further step in the right direction. Our groups can be outstanding liaisons between doctors and survivors. We help educate physicians and members alike when we invite doctors to speak at our meetings on specific polio issues. Be sure to provide everyone with reliable material pertaining to the subject at hand ahead of time. Thus we spare the doctor hours of research, and members are more able to ask relevant questions during the after-speech Q&A session.*

What all of this leads to is exactly what support groups do best: working together to produce beneficial results. Let us hear more voices, breathe new ideas into our discussions. Active groups are always on the lookout for new members, and we'll find them, since many individuals are only now experiencing the signs of PPS. Voila! There is much yet to do in our mission to make life easier for polio survivors, and infusing our groups with “fresh blood” is sure to build enthusiasm for the task. Why not go for it!

*A few excellent sources for material:

1. Jubelt, Burk, M.D. and James C. Agre, M.D., “Characteristics and Management of Postpolio Syndrome,” July 26, 2000, JAMA copyright 2000, American Medical Association.
2. Halstead, Lauro S., M.D., *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, NRH Press, copyright 1998 by Lauro S. Halstead, M.D.
3. Halstead, Lauro S., M.D., *Managing Post-Polio, A Guide to Living and Aging Well with Post-Polio Syndrome*, Second Edition, NRH Press, copyright 2006 by NRH Press.
4. Maynard, Frederick M, M.D. and Joan.Headley, M.S, *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, copyright 1999 by Gazette International Networking Institute.
5. Post-Polio Health International website: www.post-polio.org
