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Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

In the Winter 2009, *Post-Polio Health* (Volume 25, Number 1), PHI instituted the “Ask Dr. Maynard” column because he was already answering many medical questions for Members and it made sense to share his wisdom extensively. (He and other Members of PHI’s Board of Directors and Medical Advisory Committee have answered many questions over the years.) Dr. Maynard has the ability to critically analyze a situation, draw on his vast knowledge of the literature and his years of clinical experience, and then respond to each individual respecting their intelligence and encouraging them to take charge of their healthcare decisions. His approach is appreciated by many survivors, emulated by health professionals and one that I am so grateful that I could pass along to you. —Joan L. Headley

Question: *I am looking for an article that explains post-polio syndrome. The significance of finding the right article is being able to convey the information to my Uncle Phillip’s verbally abusive 35-year-old son who thinks his dad is “not trying hard enough,” and his nagging wife who is always trying to force him into physically demanding activities. He goes to bed a lot of the time in pain. I’m hoping to shed some light on the seriousness of his condition and be able to explain what his central nervous system can and cannot do even at his best. How would you explain it?*

Answer: There are many good articles that explain what PPS is and I will list some of my favorites at the end of this answer. The ideal reading about PPS for helping your Uncle Phillip would emphasize the importance of avoiding overuse of muscles in order to reduce pain and fatigue symptoms and to prevent worsening of weakness.

However, your greater challenge may be how to encourage your “nagging” aunt and “verbally abusive” cousin to care enough about your uncle’s well-being to read anything about the problems of older polio survivors.

They most likely will need a trusted authority figure, such as a specialist physician, to say that your uncle has PPS and to explain that any declines in his energy or ability to do things is due to his medical condition of PPS and not due to “laziness” or “giving in to aging.”

Your uncle himself may be in some denial about his declining abilities, possibly from a “fear of giving up” or “giving in.” He, too, may need to learn much more about PPS in order to be a better advocate for himself and to avoid being pushed or derided by family in ways that worsen his symptoms.

One strategy you may use to help convince him that YOU are concerned about his condition (based on your readings about PPS) is to make it clear to him that a comprehensive post-polio evaluation may help him.

If he is diagnosed with PPS, you and he can encourage his wife and son to come to a doctor’s visit with him where they can ask questions and, hopefully, learn to be concerned about his condition.

After all, if he loses further functional abilities, he will be less useful to them and their frustrations that lead to nagging and berating will get worse. If they can be led to become concerned, then they will want to read articles that will be of further use to their understanding of why he can’t do as much as he used to do or as much as they would like him to do.

The problem of family members not understanding or accepting declining functional abilities of aging polio survivors is unfortunately fairly common.



- ▷ Professional counseling, as well as patient/family educational resources such as those on the following list, can be very helpful for improving these circumstances. ■

Suggested Educational Resources:

Post-Polio Health Care Considerations for Families & Friends, Joan L. Headley, MS, and Frederick M. Maynard, MD, with Stephanie T. Machell, PsyD, and Holly H. Wise, PT, PhD, (2011), Polio Place, Post-Polio Health International, retrieved July 11, 2017, www.polioplace.org/sites/default/files/files/HCC.pdf

Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome, Lauro Halstead, MD, (2006), Washington, DC: National Rehabilitation Hospital Press: ISBN 978-0966167665.

Aging with a Disability: What the Clinician Needs to Know, Bryan Kemp and Laura Mosqueda (editors), (2004), The Johns Hopkins University Press: ISBN 0-8018-7816-0.

Post-Polio Syndrome: A Guide for Polio Survivors & Their Families, Julie K. Silver, MD, (2002), New Haven, Connecticut: Yale University Press: ISBN-13: 978-0300088083.

“Post-Polio Patient: Psychological Issues,” Margaret Backman, PhD, *Journal of Rehabilitation* (53:4, 1987) and *The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families*, (2006) Margaret E. Backman, iUniverse, Inc: ISBN 0-595-38639-3.

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (revised edition), Frederick M. Maynard, MD and Joan L. Headley, MS. (editors) (1999), Gazette International Networking Institute: ISBN 0-931301-04-1.