



## Improving Communication with Our Doctors

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Most physicians follow the medical model, which is generally based on the scientific method. The thorough physician would get a complete history from you and possibly members of your family, perform a physical examination, try to obtain copies of previous medical records from other medical sources, and would get laboratory and other objective tests. Routine tests usually include a complete blood count, blood chemistries including electrolytes, liver enzymes, kidney screening tests, cholesterol, and others. A chest x-ray and thyroid function studies might also be included.

*I think it is essential and extremely important to have a doctor who will listen to you. As a patient I think it is equally important for you to present your history of polio and post-polio syndrome symptoms in a concise manner and as objectively as possible. I recommend that you answer the physician's questions in a similar manner. If your doctor seems hurried, that is a distinct disadvantage for both you and him/her. It is a good idea to write some notes so you remember to tell the doctor about the onset of symptoms, when the symptoms seemed to progress, and what you have done that seemed to increase the symptoms or decrease the symptoms.*

Most physicians will formulate a possible or differential diagnosis based on the history and physical exam even before the objective test results are known. In some cases, treatment may be started at that time. After the results of the objective tests are known, often the diagnosis can be made.

*The diagnosis of post-polio syndrome is one of exclusion. The usual symptoms – weakness, fatigue, and pain – are very similar to other conditions. Therefore,*

*your physician must exclude these other possible disorders as an explanation for your symptoms. The most important initial factor is to make sure that your physician knows of the history of polio in your life.*

My initial diagnosis in 1991 was a self-diagnosis. A neurologist and a pulmonary doctor did not think that I had post-polio syndrome, but I am not sure that they knew much about it. Fortunately my primary care (internal medicine) doctor was willing to listen to what I had to say. He was also willing to read the articles that I brought him. Admittedly, I had an advantage because, as a physician, my opinions and observations were not immediately dismissed.

*As a patient, you can become frustrated early on in the diagnostic process. Hopefully your physician will be honest and not defensive and will admit if he/she knows little about the disorder. This is likely a good sign that the physician is willing to learn. If you can afford it, give your doctor either Managing Post-Polio, A Guide to Living Well with Post-Polio Syndrome (1998) by Lauro Halstead, MD ([www.nrhrehab.org](http://www.nrhrehab.org)) or Post-Polio Syndrome: A Guide for Polio Survivors and Their Families (2000) by Julie Silver, MD, now in paperback ([www.polioclinic.org](http://www.polioclinic.org)). A gesture of this type can be mutually beneficial, but I would not recommend presenting any literature with a know-it-all attitude or to a doctor with a similar attitude. A little humility is good for both the doctor and the patient.*

I often hear that polio is not taught any more in medical schools. I think this is an inaccurate perception. Infectious diseases, including polio, are taught in accredited medical schools despite the possibility that an American physician may never see an actual case. I have never seen a case of leprosy, bubonic



Why am I qualified to offer these suggestions? I have had the experience of being a patient many times in my life. I have used a ventilator since I had a permanent tracheostomy in 1970. This treatment resulted from the damage initially caused by polio in 1950. I have an intensified interest in post-polio syndrome because I have experienced its effects since about 1990.

I have been a physician since 1966, and my specialty is psychiatry. I am currently a clinical professor at the School of Medicine of Virginia Commonwealth University (formerly the Medical College of Virginia), and each year I instruct second year medical students in the technique of interviewing patients.

plague, elephantiasis, or yellow fever. However, I studied and was quizzed on all of these diseases.

*Post-Polio Syndrome is probably taught less because this disorder is a "syndrome." A syndrome is a group of symptoms that collectively indicate or characterize a disease, a psychological disorder, or another abnormal condition. The causes of some syndromes are known and others are not known. When the cause of a syndrome is not clearly known, the teaching emphasis would be on recognition. As treatment may vary or change, a precise treatment plan may be suggested but with reservation. This is the case with post-polio syndrome. For example, how much exercise is enough or how much exercise is too much? The treatment of post-polio syndrome is more individualized and less empirical than known disease processes.*

The average physician may never have a case of post-polio syndrome cross his/her office threshold. If a case does, that physician may focus on other causes before considering the diagnosis, assuming that he/she knows about post-polio syndrome and assuming you told him/her your polio history.

*Communicate honestly about the severity of your symptoms. Many polio survivors minimize the severity and dysfunction of their symptoms. Don't hesitate to tell your story with complete disclosure of how bad you are feeling or hurting. It is important for you to communicate with clarity and emphasis about what has changed and what you are experiencing. You could simply complain of fatigue, pain, and weakness, but if you explain how the fatigue, etc., is limiting, then your doctor will begin to understand. For example, if you report that walking up a flight of steps is no longer possible without resting or extreme effort, you are more objective*

*in your description than simply reporting fatigue. You, as a polio survivor, understand what you are experiencing. If the doctor has a genuine ability to empathize, he/she may also be able to understand. However, the doctor may worry about missing something that is more treatable than post-polio syndrome, such as a malignancy, multiple sclerosis and other CNS diseases, HIV, or any other disease that might present with a complaint of fatigue, pain, or weakness.*

The successful doctor/patient relationship depends in part on a feeling of comfort between the two personalities involved. The patient wants help with a problem and trusts the doctor to use his/her expertise in solving the problem. The doctor's goal is to diagnose correctly the patient's problem and initiate the appropriate treatment promptly.

*This process will be more rewarding if the doctor and the patient have mutual respect, are not competitive, and both are capable of listening with attention and interest. If a doctor does not seem interested, finding another doctor would be wise. If the doctor admits unfamiliarity with post-polio syndrome and is not interested in learning more, then that doctor should refer you to a colleague who is both more knowledgeable and more interested.*

The best outcome is to find a doctor who knows about post-polio syndrome or is willing to learn, is a good listener, is not obviously hurried, respects all of his/her patients, and takes a genuine interest in you as a patient with a problem and as a person. You will know when you have found a doctor with whom you can relate. ☞