

Henry's Helpful Hints for Living with Post-Polio Syndrome

When I was three years old, my mother became a victim of Schizophrenia. She never recovered. When I was eleven years old, I had paralytic polio. I partially recovered. These two life events were major factors in guiding my life toward a career as a physician and a psychiatrist. For at least sixteen years, I have struggled with Post-Polio Syndrome (PPS). Most of you are quite familiar with all of the manifestations of that struggle. For sixteen years, I have had the privilege of being a member of the Central Virginia Post-Polio Support Group, a marvelous group. As a result, I have had the pleasure and challenge to communicate with hundreds of PPSers around the world. I think I have learned a lot about PPS and the people who are living with this life changing disorder. In this article, I will attempt to share what I am calling "Helpful Hints for Living with Post-Polio Syndrome." Many of these hints are similar to what is now called "mind – body" medicine. Many of them are replicated in other lists and articles. I offer these hints for your review, reflection, and response. This list represents only my opinion and is not to be interpreted as anything more than that.

1. **Sleep:** Adequate, restful sleep is a major asset in living with PPS. Successfully living with PPS usually requires more sleep than before the onset of PPS. The amount of sleep may range from 8 to 12 hours. This may be all nighttime sleep or could be a combination of nighttime sleep plus an afternoon nap. Many symptoms of PPS can interrupt the attainment of this level of sleep. Problems with pain, hypoventilation due to weakened respiratory muscles, sleep apnea, anxiety, panic attacks, and depression are common sleep disturbers. Any of these disturbers need to be evaluated and treated before sleep hygiene can be improved.
2. **Pain:** Pain and PPS are like partners of misery. Every effort should be made to eliminate or reduce pain without resorting to narcotic analgesics. A variety of pain management approaches may be tried. This might include over the counter preparations such as Tylenol, Ibuprofen, aspirin, and other non-steroidal anti-inflammatory medications. Non habit forming prescription medications may help pain and sleep problems. Low doses of the tricyclic antidepressants and/or the selective serotonin reuptake inhibitors may help to reduce the daily pain level and improve sleep. If one has made a genuine effort at managing pain by reduced activity, more rest, and the use of assistive devices, then the use of narcotic analgesics would be more appropriate. Other pain management approaches might include moist heat as obtained in a heated pool, gentle massage, magnet applications, and even acupuncture. Heated pools should not exceed 92 degrees F. Massage should not be aggressive, and a trained professional should administer acupuncture.
3. **Fatigue:** Fatigue is probably the single most commonly shared symptom of PPS. Fatigue contributes to greater pain and sleep disturbance. I believe that intermittent down time is the most effective method of managing fatigue. Down time means lying down prone or supine. Each person has to discover the best balance between down time and up time for each day. For example, spending an hour reclined every four hours works well for many PPSers. Medications to reduce fatigue have proven to be of minimal effectiveness in double blind studies. Also many PPSers do not tolerate medications well and have numerous side effects.
4. **Respect new weakness:** If new weakness is detected or experienced, respect this reality and do not try to restore strength by an exercise program. Exercising with this goal in mind will likely lead to more pain and a progression of the weakness. Most of us get enough exercise just trying to maintain the

activities of daily living and trying to remain independent. Be sure that any physician or physical therapist who recommends exercise is fully knowledgeable about PPS.

5. **Blood pressure:** Maintaining normal blood pressure is most important for PPSers. Many of us experience elevated systolic blood pressure (the upper number on a blood pressure reading) after exerting some physical effort. Our heart rates may also increase during times of fatigue and minimal physical effort. If this elevation of blood pressure persists, the risk for heart attack, heart failure, and stroke increase. There are many effective medications to control blood pressure. However, beta-blockers sometimes cause side effects for PPSers. The systolic pressure should be below 140 at rest and our pulse rate should be below 100 at rest.
6. **Brain power:** Utilize your brain or intellect to compensate for the increased physical limitations of PPS. This is a process that most polio survivors have been doing for years. PPS calls for an enhancement of this same process. Read more. Read some of the classics. Audio books are a wonderful way to read without tiring your brain or eyes. If your physical disability makes it difficult to hold a book or maintain a reading posture, you are eligible for the federally funded audio (talking) books for the blind and handicapped. A simple application has to be completed by your doctor to authorize this service. I would also recommend the many benefits of owning a computer. For PPSers, the investment required to purchase a computer is usually a rewarding undertaking. You are never too old to enjoy and learn from a computer, which literally makes the world available to you.
7. **Doctors and therapists:** Find doctors and other therapists who not only know about PPS, but are interested in learning more and will listen to you. However, be cautious if a doctor tends to blame all your symptoms on PPS because we are in an age group, which is vulnerable, to many other medical/surgical problems. Your doctor should rule out other causes of symptoms that simulate PPS symptoms. Your doctor should not hesitate to refer you to an appropriate specialist if any symptoms are not explained.
8. **Herbal medicine:** Americans now live an average of about thirty years longer than our ancestors of one hundred years ago. This is largely due to antibiotics, better diagnostic and treatment techniques, improved nutrition and more prevention via vaccines. Because we have it so good, we want it even better. Thus, the herbal, vitamin, and nutrient alternative medicine business is booming. Keep in mind that the Federal Drug Administration does not have the resources to monitor these alternative products as it does prescription medications. Whether it be St. John's Wort, Ginkgo Biloba, L-carnitine, Feverfew, the various vitamins, or fish oil, be sure that your physician knows what you are taking and remember that with many of these products, cheaper does not always mean purity of the product. If an alternative medicine seems to be helping you, continue it. Nobody has found a consistently effective pharmaceutical treatment for PPS.
9. **Talk to someone:** Talk to someone who cares about your feelings in living with PPS. This person might be your spouse, a family member, friend, or even a professional therapist. Our support group is a healthy and welcome forum for talking about your feelings. Many polio survivors have spent a lifetime of containing their feelings of loss and even anger. To express these feelings to someone is very difficult, but the benefit is immense.
10. **Spiritual base:** Having a faith or spiritual base that transcends the daily activities and struggles of this life can be an additional source of personal and inward strength. This pilgrimage is a personal choice, but I believe such a pilgrimage provides a greater meaning to our time in the midst of the ages.

11. **Nutrition:** Enjoying good food is still one of the pleasures of life that most of us still can do. That is the up side. The down side is that we more easily gain weight, as we are more sedentary living with PPS. The practical advice is to avoid big meals, especially at the end of the day. Eat balanced meals with some emphasis on protein content. Maintain good hydration. Good hydration assists renal and pulmonary function.
12. **Keep your feet up:** When sitting, keep your feet elevated whenever possible. Another advantage of taking intermittent down time throughout the day is the benefit of preventing or at least reducing dependent edema. Weakened leg muscles, along with reduced motor activity, contributes to dependent edema. Chronic dependent edema can lead to possible leg ulcers, deep vein clots, and phlebitis. Complications of these conditions can result in life threatening pulmonary emboli. Wearing support hose can also help prevent dependent edema.
13. **Don't ignore headaches:** Headaches are a common sign of PPS fatigue. Have your doctor rule out other causes of headache such as hypertension, tension vascular headache, or some other medical problem. A dull daily headache is often a sign of PPS fatigue and particularly brain fatigue. Brain fatigue is often marked by word finding difficulties, mental focusing, and concentration problems. These brain fatigue symptoms are usually reversible with rest. Rest and more rest is the best treatment for the dull headache of fatigue.
14. **Pace:** Approach pacing like you would an algebraic equation. The daily physiological energy expended must equal the physiological energy stored and not exceed it. Most of us are accustomed to expending more energy than we store or acquire. If you know that a particular day's activity will result in more energy expended, plan to spend more than one day to restore and recover that energy. Balancing this energy equation over time results in successful pacing. Pacing reaps results, but not in a few days. One should practice pacing for months and years.
15. **Breathe well:** Healthy breathing and good sleep hygiene are coupled together as I mentioned in #1. Sometimes, the muscles of breathing grow weaker with the progression of PPS. Thus, there could be an insidious onset of chronic hypoventilation, which could contribute to an overall feeling of fatigue. Also scoliosis, resulting from polio may advance with the progression of PPS and aging. This process could restrict the ventilatory capacity of the lungs and lead to hypoventilation. Measurements of pulmonary function and arterial blood gases can help to diagnose hypoventilation. Most PPSers with these problems do not usually need added oxygen, but simply improved ventilation, often only at night. Depending on the degree of hypoventilation, this condition can often be treated with a C-pap, bipap, or ventilator without the necessity of added oxygen. Actually, adding oxygen without improving ventilation can increase the risk of carbon dioxide retention in many PPSers with scoliosis or weakened respiratory muscles. Untreated chronic hypoventilation can lead to respiratory failure and ultimately death.
16. **Extend recovery from any stress:** Expect to take three to four times longer to recover from an infection, minor or major surgery, an injury, accident, or emotional upheaval. For whatever the reason, the physiological restorative processes of the body and brain are delayed by PPS. When any of these stresses occur, plan on taking longer to recover.
17. **Use your sense of humor:** Many survivors of polio seem to possess a witty sense of humor and an upbeat approach to life. A sense of humor is a good way to remain innovative, creative, and positive. Keep using this attribute.

18. **Sex and Intimacy:** Sexual stimulation is good for the cardiovascular system. Be creative with this stimulation. The polio virus did not damage the sensory portion of the nervous system. Feelings, both physical and emotional, are still potentially available for expression and perception. Linda Van Aken and I wrote an article about PPS and Intimacy several years ago which is now on our website in the archives. That article attempts to address this issue.
19. **Be more dependent:** Not only should you allow others to help, but also you should tell them how to help you. If your spouse is your main helpmate, be cognizant that he/she also gets tired. If you ask your spouse or anyone else to fetch or fix things for you, be organized about your requests and minimize their physical effort and time consumed. Simply keeping a list of your needs or requests can help conserve your spouse or helper's energy and reduce the development of interpersonal tension. It is very difficult for PPSers to relinquish some controls, but in doing so, avoid trying to control your spouse or helper. Communicate what you want or need, but be courteous and grateful in the process.
20. **Roll more, walk less:** When walking becomes more difficult because of new weakness or fatigue, get some wheels and roll more. If you can still walk some and rise unassisted from a chair, a scooter might be advisable. A battery-motorized scooter allows you greater and safer mobility. Scooters are great for malls, touring your neighborhood, and even in parks. If your weakness is profound, an electric wheelchair is probably what you need. Most health insurance carriers will pay for most of the cost of a scooter or electric wheelchair. Even Medicare covers these devices as long as your physician orders it. Once you learn the value of electric mobility, you may want to invest in a van and a lift to be able to take your wheels wherever you go.
21. **Use assistive devices:** Many of us have found it necessary to acquire new braces, canes, and crutches in order to keep walking and maintain balance. Accepting this need may be a step back in time for some. Don't resist this help. By all means, do anything to prevent falls. Do what is wise and necessary. Install grab bars, elevate the toilet seat, use pick sticks, and install ramps. I think it is wise to carry a cellular phone on your person (or wheelchair or scooter) at all times. Use your brain to help yourself. Only you know what you need and what may help.
22. **Never, ever give up:** During the struggle with acute polio and its aftermath, many of us were told, "No pain, no gain." We were encouraged to overcome adversity and that it was all up to us. With PPS, we know that attempting gain will bring more pain and no real gain in the process. However, we still need to retain our persevering and hopeful approach to life. Giving up will serve no positive purpose and is a sign of depression. We should press on, but pace the race. We should be more like the turtle than the hare.
23. **To be added when a new hint comes from you.**