



## **Dr. Henry writes about Reductionism**

Have you wondered how much more your life can be reduced by Post-Polio Syndrome (PPS) and yet, you could still retain some quality to your life? Have you wondered if PPS will likely shorten your life span? Have you wondered if PPS could progress to a state where you would be more dependent and require caretakers? Have you wondered if a progression in your PPS condition could result in alienation from family and friends and a more depressed life style? Have you wondered if some new medical finding or treatment might result in an effective treatment for us? Perhaps you have wondered and pondered all of these queries. I know I have.

The reality of diseases, accidents or violence, such as war, has been with us through the ages. Any of these adversities can reduce the quality of life abruptly or gradually. The lives of Chris Reeve and the Chinese gymnast Sang Lan were reduced in an instant by a cervical spinal cord injury. Numerous war veterans and civilian survivors of wars have experienced a reduced quality of life as a result of their experience. Many progressive diseases such as Alzheimer's, Parkinson's, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Muscular Dystrophy, numerous cancers, cardiovascular disease and on and on may reduce the quality of life. I believe that PPS belongs among this group as a condition that seems to be progressive and can reduce one's life significantly.

PPS has affected us in a variety of ways much as the original polio illness did. This variety includes the new use of orthopedic aids such as braces, crutches, canes, and even scooters, electric wheel chairs, and transfer lifts. For some, ramps, elevated toilets, widened doors, and special vehicles have been required. Others spend a lot of time lying down. Some do not have the energy to concentrate, cook, clean, or even to talk for long. Often pain, weakness, and fatigue are the causative factors in this life reduction. All of this says to me that PPS can be progressive and reduce one's quality of life beyond the usual aging process.

In a decade's time, I have gone from walking with a brace and climbing steps to most places I wanted to reach to a life of mostly resting, using a scooter to move from room to room, and becoming more dependent on a ventilator. My life has been markedly reduced. In addition, I have also experienced Post-Polio brain fatigue, but fortunately I seem to have retained my intellectual function for which I am grateful. Has a reduced life style entered your life since your PPS began?

Does PPS shorten one's life expectancy? To my knowledge, there is no objective evidence that PPS impacts on life span. There is little doubt that stress can cause us to be more vulnerable to other life threatening events. You are probably familiar with the studies on increased vulnerability of heart disease among so-called Type A personality types. PPS is a realistic physical and emotional stress for many of us. Making realistic life style changes to reduce stress would possibly increase our quality of life as well as prolong our life spans. Blood pressure often increases among PPSers. It is wise to have your blood pressure measured regularly and see your physician if there is evidence of hypertension. Taking measures

to reduce the risk of falling is an effective preventive action. We all know the dangers of a high cholesterol, high fat diet. Gaining weight as a result of being less active can increase the risk of adverse medical events. Being kind to ourselves is a simple goal.

There are some PPSers who already depend on family or hired personal attendants to assist them in maintaining their activities of daily living. Most of those folks do not make it to our meetings, but they are on our mailing list and many are also on the Internet. Any of us could be in this dependent state. There are even some PPSers who "recovered" from acute polio and "passed" for normal for many years and who now find themselves in a dependent state. The "passers" are having some of the most difficult adjustments because of their level of functional loss. All of us with PPS have felt some grief over our losses. Talking about our grief to someone such as family members, friends, our support group, or a professional does help.

There has been relatively little attention given to the impact of PPS on family members and friends. The survey that was done on our own group last year revealed that over half of the responders felt that their families reacted in various ways to their PPS progression. The range of reactions ran from family members being more helpful, being in denial themselves, perceiving the PPSer as a burden, and being alienating or rejecting. Some in our group have gone through divorce and the stress of divorce intensified their PPS symptoms. Because of the depressing nature of PPS, particularly in the early stages, there are some of us who emotionally withdrew and alienated ourselves from our family and friends. If we wall ourselves off from our loved ones, they will feel rejected and find it more difficult to respond to our needs. Continued meaningful communication among PPSers, their family, and friends is most helpful to all involved.

Is there any hope for a significant new treatment to arise? There is no way to know. There is much research directed toward neuromuscular diseases. An effective new treatment for some other progressive neurological disorder might also help us. Ideally, if some medication could improve motor neuron function or if the riddle of PPS total body and brain fatigue could be solved, there might be a more effective treatment in our lifetimes.

My previous words may sound depressing and reflect a poor prognosis for PPS. I have omitted the value of the human spirit. Most of us have relied on inner resources, dogged determination, some denial of our limitations, and the spirit of never ever giving up. I believe that same spirit will sustain us as long as we are kind to ourselves. Before 1991, I felt that my life with polio was a solo experience. In the last seven years, I have met many polio survivors in our support group, over the telephone, and over the Internet. It is a comfort to know that many others have experienced the same polio pilgrimage. Perhaps you have heard the familiar words, "Blessed be the human spirit in which all things are possible." I believe these words apply to us. There are also some familiar words written by the Prophet Isaiah that often speak to me and possibly you.

The Lord is the everlasting God;  
He created all the world.  
He never grows tired or weary.  
No one understands his thoughts.  
He strengthens those who are weak and tired.  
Even those who are young grow weak;  
Young people can fall exhausted.  
But those who trust in the Lord for help  
Will find their strength renewed.

They will rise on wings like eagles:  
They will run and not grow weary;  
They will walk and not grow weak.

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