

From the Desk of Henry Holland:

Dependency

As children, we all depended on adults to provide the necessities of life. Many who had polio as children soon learned to depend on various human made devices. These devices included braces, special shoes, corsets, crutches, canes, wheelchairs and even iron lungs. In order to achieve mobility and a sense of independence, we had to rely on many of these devices. As these devices helped us function more normally, many of us denied our dependence on these devices. However, a suddenly broken brace, crutch or wheelchair would quickly confront us with our dependence. One of the realities of Post-Polio Syndrome (PPS) is the necessity of becoming more dependent. That dependence often involves the resumption of using adaptive devices long discarded or perhaps a totally new dependence on some durable medical equipment. Many writers write best about what they know or have experienced. I will attempt to do the same.

I have worn a long leg brace on my right leg since I left the Medical College of Virginia Hospital on December 18, 1950. I never ran after polio, but I gained excellent mobility with the necessary help of my brace. Despite being constructed of steel, my brace suddenly snapped apart many times. It snapped in junior high school, high school, college, medical school, residency training, and making rounds in hospitals over the years. Each time it happened, I was reduced to an immobile or crawling state and dependent on other people to rescue me. I still wear my brace to this day. Currently I take very few steps, but those steps are impossible without my brace.

In 1968 I developed recurrent respiratory failure and had multiple hospitalizations over the next several years resulting in a permanent tracheostomy and nocturnal use of a mechanical ventilator. This treatment caused immense improvement in my daily activity. I essentially denied my dependence on my ventilator because I was otherwise functioning very well. Polio had caused scoliosis and the weakening of my respiratory muscles. I have used a ventilator every night for over thirty years. My life depends on my ventilator.

By 1991 PPS had slowed and weakened me to where I needed a scooter to conserve my daily energy and to be able to continue to function at my work. This level of dependence worked until 1996 when my fatigue level made it impossible to function at my full time work. I experienced a sense of loss at many levels. After a period of adjustment and acceptance I discovered that I could work part time in a home office and this arrangement is still working.

My latest new necessary dependence occurred a month ago. My respiratory muscles have weakened over the last several years. My pulmonary doctor recommended that I carry a second ventilator on my scooter and use it almost continuously. I have done this. My oxygen saturation is normal. Breathing is not an effort. The reality of my dependence is now considerable. I am dependent on my brace to stand, my scooter to move about my house and outside, my van with a scooter hoist to travel to other locations, one ventilator at bedside, one ventilator on my scooter, the Virginia Power

Company for electric power, batteries for portable power and most importantly my wife of thirty-seven years.

My wife Brenda has always been a caretaker, but now her burden of caretaking has greatly increased. She anticipates my needs and is an unsung hero. Within our post-polio support group there are countless caretakers who are often unrecognized. Many of these caretakers are also getting older and have limited energy and muscle power. They should frequently be recognized and appreciated for their labor of love. In my judgment, Brenda is a Nobel laureate in caretaking.

How does one cope with the growing dependency of PPS? Denial is no longer a wise choice. Our return to dependencies of the past is similar to a regression, but a necessary regression and not a pathological regression. Some degree of rational thinking may help. I recognize that all humans are dependent on the natural benefits of our environment, the advantages of modern technology, the immense protection provided by vaccines, the life saving interventions of modern medicine and surgery, and the good will of our fellow humans at times of natural disasters or man made tragedies. Death is coming for everyone. Quality of life in our senior years is everyone's desire. Despite my dependencies I still have quality of life. I feel blessed. My dependencies cause me to be and feel more vulnerable, but life can often be enriched by vulnerability and even risk.

For many polio survivors the spiritual quest may be a way to cope with the uncertainty of life and the reality of dependency. For those of the Christian persuasion, the words of Jesus in Matthew (chapter 11, verses 28 to 30) speak directly to my dependence and perhaps yours: "Come to me, all of you who are tired from carrying heavy loads, and I will give you rest. Take my yoke and put it on you, and learn from me, because I am gentle and humble in spirit; and you will find rest. For the yoke I will give you is easy, and the load I will put on you is light."