

My Thoughts Are My Reality

by Carol Meyer, Greater Boston Post- Polio Association Member

This is the third and fourth part of a series about my experience in living a full life with PPS.

Over the years I've had a lot of negative thoughts about having had polio. "Why me? Poor me! I hate having to struggle so hard to breathe all of the time! I feel ugly and unworthy!" I would allow these negative thoughts to take over my mind, affect my behavior, jeopardize relationships, and hold me hostage.

Eventually many of these thoughts became like programmed tapes in my head; they became the lenses through which I looked at the world. As I got older, I became limited and stuck because of my negative thinking patterns. I became afraid to try new things. I worried about what people would think when they saw how twisted my body was. I became withdrawn. I've heard it said that a person's thoughts become her/his reality. This was definitely the place in which I found myself. My life had become as miserable as my thoughts!

As my life with PPS was at its all-time low, a friend recommended that I read a book whose author suggested keeping a gratitude journal. I decided to try it ... I didn't have anything to lose. Every day for a year I wrote down at least 5 things for which I was grateful. It was difficult at first because my negativity was so strong. Some days I could only think of items like "I'm grateful that I have a bed to sleep in" or " I'm grateful that I woke up this morning."

However, as the weeks and months progressed, I started to notice a difference in my thoughts and in my attitude. I was starting to accept my PPS. I felt lighter and happier. I was moving beyond my fatigue so that I could focus on other things in life ... like how delightful the sunbeams are when they fall upon the beads of dew on the grass, making them sparkle like diamonds. Today instead of worrying so much about what people are going to think of my twisted body, I marvel about how wondrous my body is to function so beautifully in spite of its limitations. I laugh more today and I enjoy trying something new. Positive thoughts are now bringing me positive experiences.

There are still moments when my life gets bogged down with a case of self-pity or negativity. Today though the minute I start to count my blessings, all of that melts away and I realize the joy of being alive. I've discovered that I can live with PPS and still have a wonderful life if I keep my thoughts positive. Years ago I used to lament the fact that my body isn't perfect. Today I am grateful for the body that I do have.

Reaching Out to Others

In September of 1952, when I was just 7 years old and in the second grade, polio struck me. From its onset, polio was in my face. At first I couldn't move my legs or swallow anything. While the mobility in my legs came back and I regained most of my ability to swallow, I was never a "passer" like many polio survivors were. I soon developed a very severe scoliosis; and by fourth grade I was wearing a bulky, heavy body brace to help support my back. Having respiratory problems, I no longer could run, be in marble tournaments, or play softball during recess. I not only believed that I looked different from my friends, but I also felt very different.

Later I had a spinal fusion, which helped to straighten my curvature and got me out of my body brace. I was always blessed with a lot of good friends, who seemed to accept and love me just the way I was. I worked hard and was very successful in my career. But in spite of all of these blessings, I continued to see myself as an outsider who was not good enough. The burden of my distorted body image was heavy, and it became a major obstacle in my life, preventing me from realizing my full potential as a human being.

Meanwhile, throughout the years I was always exploring and trying out different self-help programs. This makes sense, doesn't it, considering the fact that I loathed how I looked? On this journey, I finally found my way to examining my polio history ... something that I had denied and completely avoided until 2 years ago. With my husband's help and encouragement, I logged onto the Internet and typed the key words "post-polio." Presto! Up came over 3 million listings! I was completely flabbergasted! One minute I had felt completely alone in my polio-affected life, and the next I had access to millions of articles on the subject as well as thousands of other survivors who were eager to share their stories with me and to hear mine! What a moment that was for me!

Soon I was chatting with and e-mailing polio survivors from around the world! Through one of them I found out about the Greater Boston Post-Polio Association. I could hardly wait to call so that I could begin receiving the TRIUMPH and get the schedule of meetings. I was very nervous before walking into my first GBPPA meeting, but soon I felt as if I had "come home." Everyone warmly welcomed me, and I felt a great sense of belonging. I now look forward to each meeting and have found them to be a great source of information, camaraderie, and healing.

By reaching out to other polio survivors, I've been able to begin to heal the wounds of my soul that polio caused. I no longer feel alone or like a disfigured outcast in a world of beautiful people. I am who I am today. Surviving polio just happens to be one part of my history. I am working at accepting and loving myself just as I am.

Reaching out to other polio survivors has helped me to understand myself and to feel complete and whole; it has helped to fill that gnawing emptiness inside. I no longer feel trapped by the limitations of my own self-perceptions. Instead I feel free to be me for the first time in my life. In spite of being disabled with PPS, I realize that I still have a lot to give to the Universe. Reaching out to others helps to make my life more meaningful today.

I thought I would add this brief article by Carol Meyers also:

Breaking Through Denial

All of the PPS literature tells me that I must slow down and learn how to pace myself. Being a workaholic and a perfectionist for most of my life, I find this an extraordinarily difficult task. How do I go about charting this new lifestyle for myself? Part of my problem, I've decided, is breaking through the heavy layers of my denial.

Actually I've been slowing down in stages ever since 1981 when my daughter was born. It was then that I had to leave my teaching career behind because its demands were too stressful for me. My doctors told me then that I needed to eliminate stress from my life and take rests during the day. I felt as if I'd been slapped with a prison sentence! I was depressed and angry. After a long time, I was finally able to accept my life without teaching, but I didn't pay attention to the other suggestions my doctors made. I had too many things that I wanted to do; and ignoring my fatigue and breathlessness, I forced myself to continue. I was still in denial.

New Year's Day of 1989 found me with pneumonia and being intubated in Lowell General Hospital's ICU. While I did recover from the pneumonia, I wasn't able to breathe on my own. I made the decision then to have a tracheotomy, and that really stabilized my health... no more bronchitis or pneumonia. When I was discharged, my doctors told me again to get lots of rest, curtail my activities, and cut out stress. It was then that I started to take a rest in the afternoons, but I didn't pay attention to the other suggestions. As a matter of fact, I took on more projects and activities. I was still in denial.

This spring we moved; and after getting settled into our new home, I decided to do a lot of entertaining. I went for weeks without taking any rests at all, and I told myself smugly that I knew how to do this without stress! Well, by mid-August, I had collapsed! I was exhausted to the point of not being able to breathe. I canceled everything and went to bed! This pause in my life has made one thing clear to me: I don't want to continue to abuse my body the way I have in the past. Maybe now I can be free from my denial!

I have always been a very strong-willed and driven person, and I guess this has helped me to survive many polio-related health crises throughout my life. My denial, too, was a

survival and coping device. These characteristics have also worked against me! Now I must take my strong will and determination and direct it toward creating a healthier lifestyle for myself. I can no longer afford to be in denial!

I am trying to take more rests every day now, and I'm limiting the number of outside activities per week. I'm focusing on my nutrition, and I'm finding relaxing ways to use my time at home. I'm communicating with other PPSers daily on the Internet. Not only does this give me support and friendship, but I also receive much good information about PPS through them. This in turn helps me to break out of my denial.

Is this what is meant by slowing down and pacing myself? Well, if it is, I'm actually finding myself enjoying it. In fact, I think that it's going to work out for me. Good-bye, Denial!

Many thanks to Ms. Meyers for her wonderful insight into dealing with PPS.