

True Confessions of a PPS Newcomer

By Alice French

Polio 1958. Age 15. After three months in the hospital and another several months at home, I was able to walk with only a slight limp. By 1960, I had put the memories of polio into a little cubbyhole and pursued my life with vigor.

Few people ever knew that I was a polio survivor --until recently when I faced the symptoms of PPS -- alone, without much knowledge, without a doctor, and without a support group.

Nevertheless, I approached my research, my pursuit of a doctor, and my quest for a support group with the same fervor that I had approached my career. In the process, I have learned that the most difficult adjustments to living with PPS are the emotional, psychological, and social changes.

Sometimes we might forget what PPS can be like for newcomers. Perhaps my experiences and feelings will ring true for others, and it is in that spirit that I write.

Coming Out

I am one of those lucky survivors who lived a life with no visible signs of having had polio. My "disability" seemed so insignificant that I never allowed myself to discuss my polio experiences with "victims" (isn't that what the word used to be?) who wore braces or lived in wheelchairs. I was afraid of what others might think. For some screwy reason, I felt that I didn't have a "right" to say that I had survived polio.

Now that PPS has struck me like lightning, I have little choice but to join the club. And, because I have been in hiding all these years, I found myself overwhelmed with information, feelings, and loneliness. My sister surprised me by reaching out to a friend of hers who has post-polio and bringing me information about a near-by specialist and about a support group known as the Bransongoers. I am grateful to my sister, because I may never have taken that first step in self-care without her helpful nudge.

I made an appointment with the recommended doctor, a physiatrist (rehabilitation specialist), and I lurked on the Bransongoers website for several months. This past June, I attended the three-day "reunion," and it changed me in unexpected ways.

After spending three days with a whole room full of proud, competent survivors who did not question whether or not I had a "right" to be there, I breathed a *humongous* sigh of relief. I felt instantly accepted!

I am not embarrassed to "come out of the closet" as one polio survivor stated it. It is okay for me to be up front about my post-polio syndrome. The simple facts are: I have PPS, and I have certain limitations. I am not going to win every challenge. I don't have the endurance or the strength that others may have. I may be resting while they are out having fun or cleaning house, gardening, shopping, or whatever.

I still don't look like I had polio. But, I certainly feel the effects. I am determined, however, to learn new ways to contribute to our world, and I'm going to be positive about it. I will use the "good" time that I have to concentrate on the quality of my life instead of the

quantity.

I will use a wheelchair when possible; I will accept physical help when offered; and I will gladly use my rest periods to seize time for emotional and spiritual renewal as well as physical renewal.

In the spirit of my True Confessions, I must say that this change of lifestyle, this admission of my limitations, is the hardest thing I have ever, ever done. If it were easy, though, I wouldn't have had to come out of the closet!

What A Bargain!

The three-day Bransongoes Post-Polio Reunion last June was the best \$35 that I have ever spent. It was a life-changing event for me.

My husband and I learned about significant medical research, opinions, and advice about PPS. I was introduced to a variety of assistive devices and heard survivors' speak of the pros and cons of each. We saw a parking lot full of ways to haul a wheelchair or scooter in a vehicle.

Mostly, however, the Bransongoes group is about the people. I had the opportunity to interact with about 35 other polio survivors and to meet in person those with whom I have communicated on the Internet. This was a peak experience for me! Previously in my life, if I ever told anyone that I had polio as a teenager, their dismissive response was, "You don't look like you had polio." And, the conversation changed to another topic. In Branson, though, no one questioned my polio experience, and I wasn't the only one there who didn't "look like" I had survived polio.

Because of this immediate acceptance, I was able to open up (inwardly more than outwardly) to the realities of my past experiences and my present changes. I am certainly not a psychologist, but I can say that it took acceptance by others before I could start to accept myself. (Denial is far more important than the trite jokes we all use.) I suspect that others at the conference didn't realize what a huge impact their matter-of-fact acceptance amounted to in my evolution.

Most significant for me is the fact that somehow during the course of the three-day event, I was able to let go of the shame, humiliation, and guilt that I have felt about having had polio and having post-polio now.

Furthermore, the Bransongoes get together provided an invaluable opportunity for my husband to meet and listen to other polio survivors and to listen to them talk about their concerns and experiences. Even more important, he interacted with polio supporters for the first time in his life. Although he has been a naturally loving supporter, I think this group interaction gave him insights beyond what he could get from our daily home life or from any article or book.

We both began to adjust to hearing and using the PPS terminology. Prior to the Branson meeting, I did not have these terms in my every day vocabulary: survivor, supporter, disabled, assistive devices, brain fatigue, physiatrist (rehabilitative specialist).

I now have a group of friends who are able to be intuitively supportive --because they

know what I am going through. There is a huge difference.

All that for just thirty-five bucks! Not bad.

A Community of Understanding

"Don't make such a big deal out of it!" I know that's what they want to say to me. I have a way of knowing that others are thinking the worst of me, and this PPS adjustment stuff bombards me with a lot of noisy voices in my head.

In my moments of sanity, I know that my family and friends love me and want to see me adjust happily to my new lifestyle, but they have no way of understanding why it can be so hard sometimes.

Their confusion about my emotional crisis only cause s me to question and punish myself even more. Have I resorted to pampering myself?

Am I really only trying to get out of cleaning the house? Does my PPS fatigue and pain really exist, or have I "willed it" to happen? I have a sneaky suspicion that I am n ot the only one to ask myself these questions.

After months of watching me work through this emotional crisis, my loved ones spoke out loud. They said: "So. You can't do as much as you used to. That's not so bad. Many other people are worse off than you are. Just be happy that you can do what you do."

I tell myself that they are right, and I criticize myself for feeling upset. Oh, yeah. That makes everything okay. Hah!

I confess. I couldn't make these emotional adjustments by myself. With the help of a very fine counselor, I have learned to understand three things about my friends and family. They are:

1. Doing the best they can at understanding
2. Trying hard to be helpful in every way
3. They love me as I am today.

Now, I can let up on myself a little and say, "Okay, not everyone is going to understand but they don't need to. I will get through this period of adjustment and will come out on the other side a lot stronger than I have been thus far in my life."

One of the main reasons that I can accept that now is because I know at least thirty other polio survivors who do understand why it is so hard --because it has been hard for them, too.

The most important benefit of a support group is that it provides something that every person needs, a community of understanding.

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