

One Psychologist's Perspective on the Polio Experience

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[Editor's note: This is the first of a series of articles written by Margy Hull for Atlantic Tides, the newsletter of the Atlantic Country Post Polio Support Group. Linda Feinstein is the editor of their newsletter. This article appeared in the PPASS Times, May-June, 2002, the newsletter for the Post Polio Awareness & Support Society of Minnesota]

Our fearless leader and editor, Linda Feinstein, and I have been playing ping pong ever since Nancy Frick and Richard Bruno's fascinating presentation to our group last year. In particular, their research on the traumatic psychological effects of what happened to those of us who contracted polio led us to think about our own experiences through that lens. We kept seeing a lot of water in that half empty glass. Sure, as a group, we're Type A, but if. As their statistics show, we're more educated, more likely to be married than the general population, and more likely to be working than the rest of the disabled population, we must be doing something right. Is it possible that there are other, more positive influences on us as a result of what took place? What might they be? Is it only that we are so desperate to prove we are "normal"?

Linda has persuaded me to write a series of articles on some of the other psychological factors that might be involved in influencing the way we have developed our personalities. This month I am going to tackle this CONTROL business. I am particularly fit for this task because my psychologist friend Peter has crowned me the "Queen of Control." (Do I have any pretenders to the throne among my readers?) Someone else less friendly might call me a CONTROL FREAK; perfectionism and related characteristics are responsible for a hefty chunk of my Type A-ness. (Eight out of ten items in their "Type A" questionnaire appeared to me to be related to a strong desire to control, especially in the work place.) Where does this come from? Usually people develop an abundance of a quality when it works well for them, either in getting them what they want or in protecting them from physical or psychological pain. What was there about the experience of polio that rewarded us for being obsessed with controlling things to the last detail?

You want an example of control? I get asked out to dinner and I ask, "What restaurant did you have in mind?" "Do they have a ramp?", "Did you notice as you drove home from work – it's on your route home, right? – if they shoveled their parking lot yet?" "Which car did you plan to drive?" "Do you think we can be home by 9:30 pm?" "Do you like to drink when you eat out?" (There are good reasons for all these questions, of course, the last being to ensure that his coordination is at its best when he helps me with the transfer in and out of the car.) Control also is involved in my own head as I figure out just the right tone and timing to ask all this as, ironically, not to appear too controlling. I also try to protect him from experiencing the full brunt of the burden of my disability. (I don't deny Frick and Bruno's emphasis on our desire to look as "normal" as possible, so control can protect us from the pain of rejection.)

But is there a more positive basis for this control mania as well? Having been treated badly by other certainly has occurred to those with polio, but that alone is more likely to cause one to feel powerless, helpless and unable to control one's life. I believe that one factor is that we of the Sister Kenny flock got a tremendous amount of praise for working our butts off. Also, in contrast to some other disabilities, it worked, in the sense that most of us are a lot better off than when we first got sick. We were rewarded for being workaholics. (That's why it's so hard to get it into our thick skulls that they changed the rules on us and now we're supposed to conserve out energy.)

Finally, for some of us at certain times whether we can do something at all, depends on all the conditions being just right, hence the attention to detail. One inch more and I can get up from the cushion, five more degrees of temperature outside and I can work the key, a little less humidity and I can open the door.

All this concern that we work and slave to make everything just right was bound to carry over out of the workplace into planning birthday parties, painting the kitchen, patching up a fight with a friend and on and on. It may get on the nerves of those who love us, but who do they go to when they need a problem figured out? Spontaneity may not be our strong suit, but at problem solving, we're the best!

More in the next issue.

Getting Help From the Family

A response from the internet

Question: I don't think my family understands what I am dealing with in Post Polio. Sometimes, I feel they think I am just trying to get out of doing things, but that's my thought, not theirs. Does anyone else have this experience?

Answer: I think most with chronic conditions go through this. Either they think it's happening or it really is. I have a suggestion though. Ask your family members to help you learn about PPS. Ask **THEM** to do the research via the internet and so on. You'll be amazed at how much people learn when they are trying to teach you.