

In the Fall 2009, *Post-Polio Health* (Volume 25, Number 4), PHI introduced a column with a title based on the initials PPS. The purpose of the column was to acknowledge and address the fact that we as polio survivors are not only physical beings with physical concerns, but that we are psychological, social and spiritual beings.

The column's success years later is due to the knowledge, professionalism and dedication of the contributors. Their contribution to the post-polio community is hard to measure, because it is still true for many that discussing the psychological effects of having had polio is "not done." I believe that having an opportunity to read about it, though, is a good first step.

For this issue, I asked them to write about themselves. After eight years, it is time you get to know them better! With gratitude to Stephanie and Rhoda, Joan L. Headley

Response from Stephanie T. Machell, PsyD:

My dad had polio at age 33, a few years before I was born. Once he was released from rehab the vocational counselors at Morgan Memorial signed him up for a milk-testing course. He did this job, which involved standing for hours in cold barns and lifting 50-gallon milk pails and jugs of sulfuric acid, full-time for years. Until he broke his polio leg he continued to do it part-time while working full-time as a herdsman on the farm at a state school for people with developmental disabilities and in a factory where his math skills got him promoted into accounting.

By the time I was six my dad gave up his brace and crutches. He walked with a heavy limp, but with the exception of driving a standard shift he found ways to do everything that mattered to him. I thought it was cool he could do things like climb a ladder, "bad" leg flapping in the breeze while his "good" one (and arms) did the work. But it was just what he did, not heroic or inspirational, though watching the effort surely contributed to my work ethic!

Polio left Dad with more than a "bad" leg. Throughout my childhood he made meaning out of what was clearly a traumatic experience for him through a narrative of misdiagnosis and confusion, pain, creeping paralysis, rehabilitation and recovery. Though this likely contributed to my adult ability to tolerate trauma narratives, it also made me prematurely

aware that we're all eligible to develop life-threatening conditions.

By the time I graduated from college he was on SSDI because no one wanted to hire a 59-year-old with a disability, even someone more than willing to work. It wasn't long before he began experiencing weakness, again walking with a brace and crutches as well as needing naps and rest breaks that allowed him to remain physically active, working on my cousin's farm, gardening and taking long walks with my mom. A few months before he died at age 88 he was still shoveling snow for his neighbors, falling constantly because dementia made him believe he no longer needed a brace. The way he lived with PPS showed me the importance of doing what gives your life light and color.

As they aged, my parents remained fiercely independent. Neither wanted my brother or me to become their caregivers, which taught me that while family caregiving is right for many people, it can be a bad choice for others.

Some lessons are taught by what didn't happen. Though they communicated their caregiving wishes, my parents were secretive about their health and other important issues, to a degree where not knowing became burdensome to us offspring, due to wondering if things really were all right with them. And my mother's difficulty in talking about her own issues meant that by the time she disclosed that she'd prob-



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ably had polio when she was four she was near the end of her life.

I wish we could have discussed these things. I've never heard a family member complain of having too much information. Of all the things I learned as the child of polio survivors, the importance of communication about needs and experiences is perhaps the most important.

Response from Rhoda Olkin, PhD:

When my son was five-months-old I dropped him on the rug. This might be the nightmare of every parent with a disability. He's 30 now, so I guess he survived. But I never felt as disabled as I did when my kids were babies. Having lived with polio since age one, I was used to being able to do most of the things I wanted to.

But early parenting involves lots of lifting and carrying — into and out of cribs and car seats and highchairs, from floor to changing table. If I couldn't figure out how to do some of these things on my own, I couldn't parent independently.

I learned adaptations, as did they. I bought a large scooter, affixed a bike seat to the back (for my son) and a large basket onto the front (for my infant daughter). I attached a ladder to the changing table and taught them how to climb as early as possible. They never ran away from me (no fun in that if I didn't chase them) and learned to stay within voice distance. We did lots of crafts, and on my slow days we sat on my king-sized bed eating pizza and watching TV. When my foot was swollen from heat, my daughter and I did "upside-down reading"—laying on our backs with our feet elevated.

The early years of parenting were all about physical accommodations. The tasks of parenting elementary and middle school kids were carpools, activities and playdates. By then I was well aware of the effects on me of parenting with a

disability. But I didn't know the effects of having a mother with polio on them.

Turning to the professional literature on parents with disabilities was disheartening, as there were many problems in the studies: conflating disability with illness, ignoring key differences across disabilities, and examining only negative effects.

Consequently, I, along with colleagues at Through the Looking Glass in Berkeley, conducted a study on parents with disabilities raising teens. We gathered perspectives from the parents and their teens, and comparison parents without disabilities and their teens, who lived in the same neighborhood (Olkin, Abrams, Preston, & Kirshbaum, 2006).

We found that the families were more alike than different: same bedtimes, same number of dinners eaten as a family per week, equal attention to homework.

But there was a key difference—the families in which a parent had a disability had about \$15,000 less in earnings per year than the comparison families, and they paid more out of pocket for assistive technology and housing accommodations. This is consistent with my own experience; about 20-25% of my salary goes to out-of-pocket disability-related costs.

There are many things I wonder about in terms of my (now grown) children, regarding the effects of my disability on them. I would like to think they are more sensitive to diversity and differences than their peers, but in the study just cited we found that all parents believe this to be the case for their children.

I know they worry more about me, about my falling, or needing more physical and financial help, about increasing fatigue. These are my worries too, but I wish they were not my children's worries.

They still turn to me for their needs, which is as it should be. ■

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