

Here is my own story - Laine King - Survivor Guilt

International Post Polio Conference. First time for Atlanta, first time for me. I almost had some kind of breakdown the night before, just knowing that I was going to a place where there were hundreds of crippled people, not people like me but crippled people. The ones that you look at and feel sorry for and you're glad it didn't happen to you. And you know it should have happened to you, and it did.

Summer means one thing to you when you have something to hide. Exposure. Those people at the conference can't hide. They have to carry their signs around with them. Oh yes, I'm guilty. At the age of four, I got in the way of a virus, wasn't smart enough or quick enough or strong enough or good enough to stay out of the way of the virus. Just like I wasn't strong enough or good enough or brave enough to get away from my brain damaged cousin when his hands would come sneaking under the sheet to touch me and make me ashamed and I can't tell anybody. And it's my fault I'm crippled but I can't let anybody know and I can't tell anybody and I am ashamed.

Now I am going to a conference of all these other shamed people and I will say I am one of you but I haven't suffered as much as you. I haven't carried around the steel and wood and plastic and pain for all to see. I covered it up and pretended it wasn't there and when others ask, are you limping?... I say, I'm just tired. It's ok. It was just polio. No problem. No cripple here. Don't tell. Nobody will know.

And then I went. I went to the conference. And there they were. Riding around on their little scooters of every type, sporting every type of cane and crutch. High tech, high mobility, high spirits. In spite of the news, which is not good, and the physical states, which were not strong, the spirits were optimistic and dedicated to self-education and survival. These are, after all, the Polio Survivors. That's what we're called. Polio Survivors. And here I am, suffering from Survivor Guilt because I can walk in unsupported wearing semi-Normal shoes, with an almost-Normal gait. I can breathe without assistance. I could be one of the medical practitioners, you can't tell from looking at me. I might not be a Survivor. But I am. A lucky one. I got good care from the beginning, back in 1949. Lots of them didn't. I had surgeries that accomplished the purpose of keeping me walking without pulling other joints out of place. I'm sorry that I walked in and they didn't. I wish they were all as lucky as me.

Everybody is smiling and trading tales of hot wet wool and childhood indignities so profound that they demand to be treated lightly and everyone smiles and laughs and adjusts in their seats and remembers. Or not. Some don't remember the fork in the karmic path, the experience which created and defined their life from that moment on. They seem to feel deprived; they want to know the reality of the crippling blow, to own it as it owns them. They complain of amnesia, questions its origin. Was it the fever, the trauma, should I get hypnotized? Some say, with regret, I was only 2. One, the one who sat by me with her little legs in the plastic and metal and leather braces and her little feet in the plain white shoes with no cute little straps and no cute little bows, this one said: I was paralyzed from the neck down at the age of five months. And a hush hits the room like a quick small wind and then the discussion goes on. They don't remember what the rest of us remember, the night of body breaking pains and fevers and nauseas and stiffness and spinal taps and quarantine and abandonment and fear and muscle spasms that contorted the body so that some medical practitioners put them in a body cast and the spasms kept right on happening anyway.... and he laid in the cast and screamed for two days. They don't have that shade of childhood memory and they feel cheated.

They talk to us about the reasons we have all begun to regress, to lose the strength we gained so long ago and held day by day only to slip back into conditions past. Post Polio Syndrome, it's called. Some who have walked have reverted to braces and crutches; some who breathed outside the iron lung now have permanent holes in their throats covered by colorful bandannas. Some who moved on crutches are now on scooters and wheelchairs. They tell us that No, it's not Polio happening again. It's just that any one or all of the following changes is happening because Polio happened to you long ago and the cause is this or that or both and it is causing any number of the following symptoms and it might happen to you and it might not and it might go all the way to fill in the blank or it might not. But it's pretty likely that you wouldn't be here if you weren't already having some of the symptoms, so inform yourself, do the right thing with your body and get your head right for what's ahead. And be sure to see our nice vendors out in the hall with several different types of wheelchairs, scooters, braces, canes, crutches, treatment plans, oxygen dispensers, van conversions and electromagnetic devices which may or may not alleviate some of your pain.

I am not the only Lucky Survivor. The other Normal looking ones are the other Lucky Survivors. And when I talk to them, they, like me, are getting new information here. They, like me, have never been around a bunch of full-tilt Polio Survivors before, in full wheel. They, like me, are scared to death. This is scaring me to death, the white haired man says. He had paralysis in the right arm and shoulder and left leg, got quarantined with his grandmother who, one day, took off his shoulder brace and said, you're not ever going to get strong with this on and she massaged him with olive oil every day and one day he got this excruciating headache and his head started drawing back and they rushed him to the hospital arching ever further back and they put a needle into his spine and drew out fluid and his headache went away and his neck stopped arching and he was ok. Only he had no muscles in his right arm and shoulder and his left leg, but that wasn't anything that couldn't be overcome; and he looked Normal to me. Another man who says that he was the baby in the family and a shy quiet little boy, he says, this is scary. He was paralyzed on his whole right side and he's always had problems, but he had good care and he coped well and he's had a pretty Normal life. His wife makes fun of him and accuses him of malingering and using Polio as a handy excuse when he says that he is tired. He looks at me with his sweet eyes behind his little round glasses and we recall the way it was and we express our plans to cry when we get home, but not now.