

For Parents

by Kevin, an adult with hemiplegic cerebral palsy

I can say what I am about to say perhaps only because my hemiplegia is slight--- affecting primarily my walk, left foot/leg size and the motor skills of my left hand. It was however severe enough to warrant four operations, years of braces, therapy, and ugly orthopedic shoes.

While I feel that I got off lucky, the experience of hemiplegia not only scarred my life as a child, it in essence became my life. Here, though is the odd part: My disability, perhaps because I willed it to do so, changed my personality and the essence of who I am for the better. While it made me an outsider, it also gave me compassion for all outsiders. While it forced me to suffer physical pain, it gave me the ability to respect and empathize with the pain of others. While it drove me to the very depths of sadness as a child, I also learned early to laugh (at hemiplegia, at the slings and arrows of life) and have a strong, sardonic sense of humor that I carry to the present. While it made me different from other kids, it caused me to come to grips with the good things inside me that truly made me different and special.

The final odd part: I am who I am in large part because of my disability. If some magical omnipotent entity came to me now (as I dreamed and hoped as child that someone would), within a few months of my 45th birthday, and said that it would remove hemiplegia from my life entirely --from the beginning--and with it all the changes in my being and personality that came with it, I would respond with a polite but firm "NO". I like whom I have turned out to be, funky walk and all, and I value too much what I have learned in my personal school of hard knocks. This is a personal statement, and applies only to me. I am not a masochist and, if my disability were greater, I am sure I would not respond with the "NO". I am humbled by the levels of pain and compassion and worry and hope and love on this list of parents of children who have hemiplegia.

I sympathize, in a way few people can, with the pain that hemiplegia has caused you as parents who love your children. The things I have learned from hemiplegia are not gifts but silver linings amid dark clouds. I am a great believer in silver linings. I want to give you the thought that there might (and only might) be some small good things that your children have received or will receive in life, which may be linked in some way to hemiplegia. At least this is my hope.

Kevin