

When a child asks why?

By Whit of Newton, MA, 4 Jul 1999 in response to an eight year old boy's question about why he has cerebral palsy

Dear Michele,

Your story really touched me, and I'm glad you posted it. It seems to me Patrick is at one of those "nodes" kids get to in their development. The fact that he can say these things to you, and ask you these questions, is **so** important. It says a lot about how much he trusts you and his feelings. Maybe, hard as it is, you should thank him for this. So much of the talk on this list is necessarily about the physical accoutrements of life with CP--the AFOs, the surgeries, the Botox. So much IEPs and advocacy and where to get resources--again, practical stuff.

And we post so many stories we tell ourselves to make ourselves feel better. We share poetry that romanticizes our children (angels), and ourselves as chosen people because we happen to be their custodians. We dream of Disney World not as fun, but as some kind of solution--a world of Peter Pan, with a hovercraft wheelchair (!) in every van.

So.... Now Comes Patrick stepping up to the podium and asking you the very hardest question of all: Mommy, why me? What's the deal? Why can't I (a, b, c)? Can't you fix it?

This, it seems to me, is where the rubber hits the road for a parent, and where so many dangerous blowouts occur because we crumple. We claim to want to protect our kids, but what really happens is we can't face our own grief and anger and guilt. To be able to look your child in the eye and say, "there is no good reason." To say "I hate it too" but "it doesn't stop me from loving you." To say "because bad things happen to good people." To say so far there is no new medication or breakthrough therapy or magical fix but there is a LOT we can do.

Julian and I were driving somewhere when he was about Patrick's age and he asked started asking me Patrick's exact questions. I remember pulling off the road and parking and listening to him say he felt like an alien sometimes, like somebody from another planet, like god had played some kind of nasty trick on him, or worse, maybe was punishing him. I remember reminding him he was not an alien, that this was not some kind of punishment, that he was the best boy I had ever met. I remember saying how a million times I had wished I could somehow trade places with him--that I could be the one to take the CP because I was older and more experienced and maybe I could handle it better--let him be the one with a standard-issue body. This was of course the first of many conversations along these lines, conversations that have changed and evolved

as he's grown, but two people sharing so many tears and hugs in the front seat of a beat-up Buick you haven't seen since the drive-in and Gone With the Wind.

Because life is hard, that's why. BUT I'm here for you. I will help you as best I can and you will do fine. I've rounded up a whole lot of smart people to help both of us. And you are going to have to face a whole lot of hard stuff in your life, maybe more than a lot of people have to face, but then again not as much as a lot of others. Some of this will make more sense as you grow up. Some of this won't. But you'll be ok. And I'm with you--remember that.

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