

## Why Not Me?

My name is Holly, I am mom of Melissa, a child with right sided hemiplegia. In reading your letters it brings to mind a lot of things about being a "special" parent of a "special" child. I have seen a lot of "Why me?" letters and replies. This is a significant stage of grief that a person goes through facing a loss. In a different, but similar, way we have all faced a sort of loss (of a "normal" child), but is it really true?

Many of you might be familiar to a book, "On Death and Dying" by Elisabeth Kubler - Ross.MD. It covers stages of grief which include: denial, anger, bargaining, depression, and acceptance. What did I (we) do wrong? Who made this happen to me (us)? In many ways, we as the parent(s) of children with cerebral palsy go through a grieving process. We are at first surprised or shocked, then angry with the question "Why me?", maybe even "Why the child?". We may even look at others and wonder how it is that some with many problems have a surprisingly healthy and normal child and we do not. We may feel life is not fair. We wonder sometimes if things are different or if we do something, we can change everything around and receive a different outcome. We may become dispassionate about everyday life, and wonder what is life all about. Or feel tired and frustrated with it all.

And then somewhere down this self-journey we realize this is how it is, and we accept it. I have been through all this myself, the only difference we have between this and grief of forever losing a loved one, is this child is a survivor, and will live on with this CP in some unknown way. The world of medicine does not have all the answers about what will be the future. We live not really knowing what to expect. It all unfolds as life goes on.

This is not an easy life, but I sort of turned it all around, and asked "Why not?". Having a CP child is not easy, not by any means. It is a challenge, and also a big challenge to the child who has it. How I worked with it was this way. I was somehow given a gift. I was given this challenge, and have a lot of love give, and take great joy in the amount of love I receive back from my daughter. She has changed many people's views on disabilities over the years, opening eyes of people that may have never encountered a closeness to something like this in their own lives. She is a gift in her world of struggles, and smiles and laughs often anyway.

Heartbreak, pain, tears, fears, frustrations, accomplishments, surprises, love, laughter, and smiles. And these are all in such a wonderful level of magnitude in our life. My daughter took her first walking steps for many, walking down the aisle of a church where my younger sister was married. She was 5 years old when she learned to walk alone. A vision or memory I have planted in my mind is warmly beautiful and still makes me smile. The memory is that of my 5 year old Melissa

walking along alone, for her first time, with a basket of flowers, down that church aisle, before a big crowd, with the biggest darn smile of accomplishment, happiness, and pride. She was not afraid and unaware of the tears of joy in the eyes of people that knew her and her struggles. Friends and family were so pleasantly surprised.

She has brought an immeasurable amount of specific joy and enlightenment to many lives she has touched along her road in life, and will continue to do so. And every first of hers is a special joy. So I have also asked the question "Why me?", and I have also answered it for myself. It is because I (we) have been given a special gift in life of a special kind of joy - very challenging and also very rewarding.

Holly

mom of Melissa, she is now 19, and has right side hemiplegia and aphasia (no speech), history of seizure disorders, challenged and challenging, CP is from spinal meningitis at 3 days of age, and she has a gift to give.... she has a basketful of smiles to share with the world around her.