



Complex Child E-Magazine

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Coping with Neurological Impairment

by L. Kelly

My pregnancy with my first child was a joyous time. I loved every minute of it. We had a wonderful time painting the nursery, picking out tiny little clothes, and making plans for her life...the “important” stuff like what sports she would like, when she would learn to read, and what college she would attend. The birth of my daughter six weeks early was a surprise, as was her need for a stay in the NICU.

As first time parents, we didn’t know what to expect and were quickly comforted when told that the tests looked normal and everything would be OK. Slowly, over the next several months, we began to realize that things were not OK and at six months, while hospitalized for severe seizures, we experienced the worst day of our lives: the day when the doctors converged on our daughter’s room to break the terrible news that things were not only “not OK,” but were in fact very bad.

We were left to pick up our shattered dreams and try to move forward. When I look back on that day, I can still feel the tension in the room, feel the air being squeezed out of me, and see the look of anguish on my husband’s face. I try to avoid thinking about it too much! It doesn’t do much good to linger on the things we can’t change. It mostly makes me feel worse.

If you are taking the time to read this, you most likely have a child with a neurological or other impairment in your life. You have experienced the same emotional rollercoaster that I ride. And you very likely have a day like this in your memory.

Learning to Cope

There are two major occasions I dread: birthday parties for children about my daughter’s age and Halloween. On these days, I’m reminded of just how different my life is. All of my coping mechanisms seem to disappear. On these days, I loathe having to politely answer questions and respond to comments that well-meaning on-lookers ask in an attempt to include my child in the festivities.

“No, we won’t be trick or treating this year, she just doesn’t like to be outside.”

“No, she doesn’t miss the candy.”

“No, she can’t have a piece of cake, she just can’t swallow it.”

“And no, thank you, ice cream doesn’t go down any easier.”

“No, she can’t walk, even around the house.”

You get the picture.

I like to think that 99% of the time I cope with the realities of having a child who is severely disabled and neurologically impaired quite well. It’s that one percent of the time that gets me. And that one percent for me includes birthday parties and Halloween.

So how do I make it through the day when we don’t have to attend a birthday party or celebrate Halloween, the other 99% of the time? It’s not exactly one thing in particular.

First, I let myself be sad sometimes. It’s fine to have a bad day, to feel sad, and to cry. No matter how much I love my child and how well I cope, the pain of our lost dreams runs very deep and will never go away. Sometimes the stress will seem overwhelming. There are times I just need to feel sad and cry a little. It may start with an unkind comment, evaluation results, illness and hospitalizations, or special events. It may be a way to deal with the stress of dealing with Social Security, insurance, medical bills, or spending more time in doctor’s waiting rooms than at home each week. A good cry is a release and I nearly always feel better after.

Second, I take breaks. For me this means using respite hours and having a few activities at home that allow me an “escape.” I feel incredibly lucky that the state we live in provides my daughter with nursing and respite care. It took me a long time to accept that I needed to trust someone else with her care from time to time and take a break. But it’s amazing what a couple of hours out of the house and a nice dinner will do for your mood (not to mention your marriage)! At home, I love to read, so once a week I sequester myself in the bathroom for a nice long soak in the tub with a good book. The time away from the front lines, so to speak, recharges my energy and helps me refocus on my beautiful daughter.

Third, I have a good support system. Unfortunately, there’s not just a magic support system waiting in place for each one of us. Service providers, like your therapists, social workers in the hospital, and early intervention workers, are really good at suggesting you find a support system, but they often don’t have any suggestions for where you can find that system outside of your family and friends. Some families just can’t be there the way we need them to be for whatever reason (that would be mine). Friends who don’t have children with neurological issues often just don’t “get it.” My pre-child friends fit in the “just don’t get it” category. I love them, but it’s hard to discuss your child’s brain surgery and have it compared to their neuro-typical child’s vaccinations. I know many

find great support from their church communities; I just haven't found one that is the right fit for us.

If you live in a populous area, there are probably some support groups for families with special needs. Try contacting your local branch of the Arc of the United States [www.thearc.org] or United Cerebral Palsy [www.ucp.org]. In my area, both organizations hold organized support groups and parent/family educational and fun events. The best part of these events is that they usually provide childcare and are ready and equipped to handle your child's special needs. Every state also has at least one Parent Training and Information Center [<http://www.taalliance.org/ptidirectory/index.asp>], and our local branch usually has a list of events and meetings, in addition to the training sessions and movie nights they host. These are great opportunities to meet other parents who are dealing with similar circumstances.

If you live outside of a city, you'll find that these groups are few and far between. We spent a couple years in the rural Midwest, living in a town of less than 200 people with the largest town nearby having only 15,000 people. If you fit into this category, I feel for you. Everything you read suggests seeking out local support groups, but there's just not much available.

I'm a big fan of online support groups. I can't stress enough how much benefit you can get from talking with other parents who are in the same boat. Check out Yahoo Groups [<http://groups.yahoo.com/>]. They have thousands of very active email support groups for nearly every disorder you can think of, even most of the rare ones.

There are thousands of other online groups available but here are a few options that I've found to be safe and reliable:

- ❑ **Epilepsy Foundation eCommunities** [<http://www.epilepsyfoundation.org/efforums/forum/index.cfm>] and **Epilepsy.com** [<http://www.epilepsy.com/>]: seizure related discussion forums
- ❑ **Braintalk Communities** [<http://brain.hastypastry.net/forums/>]: a large, active community with general neurology and specific neurological disorder forums including one specific to child neurology
- ❑ **Parent-2-Parent and Reflux in Children** [<http://parent-2-parent.com/forum/>]: a large, active community of parents who have children with health concerns of all natures and degrees

In the end, it's about figuring out what works for you. There's not a "For Dummies" book available when you have a child with a neurological impairment. Parenting will not be like you expected it to be or like what you've experienced with your other children.

There will be times when simply making it through the day is the best you can do. There will be days when you think that if you hear another person tell you what a "strong person" you are, you'll snap.

My life is a work in progress. I get through it one day at a time, or sometimes, one minute at a time. I rejoice in the positives and I mourn when I need to. At the end of the day I try to remember this quote by Maya Angelou: "You did what you knew how to do, and when you knew better, you did better."

Tomorrow always brings a new day.