



Complex Child E-Magazine

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Balance

by Nicole Swiers

Balance.

I'm sure we all use that word from time to time, but I think as a parent of a kid with special needs it becomes an integral part of everyday life.

The hardest thing I've had to learn is to balance genuine concern versus anxiety over the unknown. I usually can tell when I'm leaning more towards the anxiety side of things, and yet I tend to get stuck there anyway.

My son has a primary mitochondrial disease. There are a lot of unknowns when you're dealing with a not well-understood disorder! They are multi-system diseases that can range anywhere from very mild to life threatening and ultimately terminal. No child is the same, which means no one can ever tell you with one hundred percent accuracy what to expect.

When you don't know what to expect it's hard not to wonder if that increase in seizures is the beginning of something more, a sign that "something" is progressing or just a blip. Are those few weeks of a terrible appetite and increased reflux just a cycle that will settle down soon, or does it mean something isn't functioning as well anymore and might never be the same? You can never know for sure.

I can choose to ride things out for a while, maybe put a call in to the doctor to let them know what's going on. Or I can search online until the wee hours of the morning every night for the next month to try to figure out what the typical pattern was for other children when their GI systems started failing them.

Concern Versus Worry

The difference between concern and worry is that concern is real. Something is really happening right now that I'm dealing with. Worry is what I think MIGHT happen in the future. Worry can consume your life. It's hard not to always be "waiting for the ball to drop."

Optimism Versus Realism

There's also the never ending quest of balancing optimism with realism, hoping for the best while knowing it might never be achieved, at least not in the way you'd hoped or expected. It's the balance of living completely in denial versus choosing not to look at those things that either you can't change anyway or that are too hard to face, at least for now. It's pushing your child to do his best and reach his full potential and realizing that full potential is different for all of us.

Creating Balance

For me, taking one day at a time and relying on my faith are the only ways in which I ever experience contentment. The contentment may last a few days or maybe just a few short hours. It really is a daily struggle and as soon as I start pondering the future, thinking about a prognosis, or contemplating all the "what ifs," I'm drawn into anxiety again.

As a parent of a child with special needs, there is not a one-size-fits-all approach to finding balance. We all deal with incredibly different struggles and some struggle more than others. But there are quite a few things we all have in common. We all want the best for our children. We've all learned that sometimes there's no other advocate besides you and that can be a scary thing. It puts a lot of weight on your shoulders and so therein comes the need for balance. Much easier said than done, but definitely something worth continually striving for!

Nicole writes a blog at <http://www.my3peanuts.blogspot.com> You can also visit Emeric's Caringbridge page at <http://www.caringbridge.org/visit/emericswiers>