

Life as a Chiari Parent...What They Don't Tell You

November, 2012 - My 7 year old daughter was diagnosed with Syringomyelia, Chiari I and Scoliosis last February. She has since had decompression surgery but recently had an unexpected regression that the doctor's can't explain. The articles on this website are filled with great educational details revealed by brave soul baring stories retold in an effort to help a helpless community. I am humbled and impressed by the depth of knowledge and understanding parents seek to help their child.

However, tonight I would like to share another perspective.

It occurred to me driving home from our Orthopedic and Neurosurgery appointment last night that in reading all the advice that people give you when you have a child diagnosed with a chronic illness they never tell you what really happens to you as the parent.

It's isolating. You realize that you can't talk to the same people you used to. That you will avoid people that are well intentioned but tell you about the famous doctor that can cure a rare disease from reading a palm. Wouldn't that be great if it was just that simple.

Your appetite changes. I can't remember the last time I ate a meal I enjoyed. Your worry for your child resides in the pit of your stomach and overtakes your need to have that great steak or a glass of wine consistently.

Your attention span is minimized. For the longest time after my daughter was diagnosed I could not read, watch television or a movie. I simply could not focus on anything that wasn't about her or making her well. It's like your heart turns into a human stress ball- some new anxiety appears and squeezes tight and your concentration evaporates.

You become temporarily inarticulate. As you tell your story over and over, you realize it is utterly draining. You leave out key details because you have already fixated on new details in the hopes that they might unlock the never-ending mystery of the true origin of Chiari and Syringomyelia. You constantly weigh your words in conversation because you do not want to appear negative or worse, be perceived as a martyr. Why would you exaggerate your child's condition when you are praying someday you can brag about her miraculous recovery?

You become irrational about the little injustices. After eight hours holding my daughter's hand and navigating her and her doll's baby stroller through the city streets and four appointments later-I never once lost my cool...until I reached her specialists office. There they gave her a paper gown for an adult that was too big and made her cold and uncomfortable. This is the demarcating line where my rational behavior ends. I get mad and tearful. It didn't make sense why a pediatric office treating sick children does not make every effort to make them comfortable. It feels cruel. A moment of comfort and warmth during a bad day is the type of thing we want and should expect to count on.

There is also joy. Yes, joy. As other distractions fade away and you lose touch with the people that are not so significant after all, avoid Facebook and the blackberry, and stop tuning into your must see tv; you realize no matter how painful- you are focused on the right thing. Your child. The child who you brought into the world, made a silent promise to protect and said you loved ten times just today. You know that you are so attuned to every movement, breath, pain, and accomplishment that you will not miss a thing even when it hurts to look.

In my quieter moments I tell myself this is not where I want to be but where I should be. My child and I have bonded our souls in a way that wasn't even possible before. Each laugh is a triumph. Every trivial opportunity to spoil her is taken. I am present even with the pain and worry and for that I will be eternally thankful.

This is my perspective today and for that I am grateful.

-- Tracee M.

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