



Complex Child E-Magazine

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“I So Tired”

by Amber Ferrell

There is something so special about rocking a child. Wrapping your arms around that warm miniature body... patting his behind with one hand and running your fingers through his hair with the other as your hearts beat against one another. Your calves getting a mini-workout as you use tip toes to push off the ground in a rhythmic rock back and forth, back and forth, as you try so desperately to lull the child to sleep. There is something so special about this time... about the closeness you experience for those few minutes. There's something precious about the stillness and contentment that happens as your child's eyes flutter into the initial stages of sweet slumber.



Rocking my children has always been one of my favorite pastimes, but lately my heart has become heavy each time this scenario plays out with Nathan. Hoping that it is a transient issue like so many other symptoms with Mitochondrial disease, Nate has been having an increase in his level of fatigue lately. He can still run around and play like a normal kiddo for brief periods of time, but his little body seems to get exhausted quicker and stay that way much longer than most.

This level of exhaustion is hard to witness. My heart literally hurts each time he comes to me saying, "I tired, Mama. I so tired." To hear a two-year-old speak that phrase over and over most days is tough, as toddlers are typically known for their boundless energy and rowdiness. I have personally never before heard a two-year-old express his exhaustion in words.



For most parents, the solution is simple. Your child is tired; make him sleep. Oh, how I wish just mundane sleep would prevent my son from coming up to me with those droopy puppy dog eyes while muttering the pitiful phrase of, "I so tired." Additional naps and rest times are added during these periods of utter exhaustion in hopes of helping him "catch up" on whatever energy he is lacking, but it seems to all fall into a deep dark hole these days. Sure, he has good bursts of energy from time to time, but mostly, he is just...so...tired. And it hurts to see him that way.

We try to make life as normal as possible for Nathan and the girls. Our days are filled with school drop-offs and pick-ups, grocery store outings, cartoons, books, and play dates. Naps for the little guy fill a majority of our day, but we still do get out and enjoy the day. Is it all too much for him? Is he fighting off some illness? Is it that awful phrase that none of us like to utter: "disease progression?" Is it the heat from these

scorching summer days? These are questions that I ask myself every single day that he struggles like this. We seem to constantly be battling with how much we want to do as a family and how much Nathan can handle, but we seem to never know how much is too much until he crashes. Will we ever find that right balance?



Some days are just difficult. Some days I wish all of this would just vanish and I wouldn't have to wonder over and over why my son has dark, sunken eyes and the desire to sleep or just sit and stare at the wall for a good portion of the day. Some days I want "normal." Some days I want my heart to stop hurting, my mind to stop going to dark scenarios, my brain to stop going through the medical checklist it has memorized in this journey. Some days I want to go back 10 years when my major concern was whether the new shorts I bought showed too much of my larger than average thighs.

Some days are just difficult.

Amber Ferrell is a stay-at-home mother and advocate for Mitochondrial disease awareness. She and her husband, Jay, reside in Central Florida as they tackle the wonderful task of raising their three precious children. Their youngest, Nathan, was diagnosed with Mitochondrial disease shortly before his first birthday. Amber frequently

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