



Complex Child E-Magazine

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Seasons of Love by Tonia Rowe

On January 29, Bella celebrated her eighth birthday. Every year I am amazed at how much she has been through and achieved in her short time on earth. As any of you who have children with special needs know, there are many emotions you experience over the years with them.

It starts with the pang of uncertainty and doubt when faced with the initial diagnosis. Will I be able to handle this? Am I strong enough to make the right decisions for them? How will this affect the rest of our family?



This time reminds me of Winter. The world feels cold around you, and all you see for miles is the snowy path that seems slippery and unsure. Hearing that Bella had moderate brain damage after her illness, and that she might never walk or talk, left me on the floor gasping for breath. Soon after, we learned the illness had also left her with profound deafness. It was as if a wintry blizzard had overtaken my mind. All I could see was a complete whiteout. I have learned to cope with this season by continuing to put one foot in front of the other even when the ground feels so unsteady that you are sure it will crumble. Making forward progress is important in order to move on to the waiting seasons.

Just as in nature, when you are sure that the rest of your days will be filled with icicles and freezing temperatures, it is then that you hear the faint sweet song of a robin. At first, you question if you really heard anything at all or if it was just wishful thinking. I can remember hearing Bella say "kitty" for the first time and thinking I was imagining it. We worked for months when she was a tiny infant to have her roll over on her right side. It was extremely difficult for her to coordinate her muscles on her right side due to the brain injury from the meningitis. Then one day she did it!



Spring is all about hope and renewed faith. It is truly wonderful to see hard work from therapy pay off in a miraculous moment you feared you might never see.

After the first buds of promise come in Spring, Summer comes close behind. Full flowers emerge and the world is green. It is easier to think about possibilities and also how to attack challenges when the sun is shining warmly on your face. Progress is being made, and while there are always some challenges that arise, they are not overwhelming at this point. I think back to when Bella began walking with unsteady steps around 16 months. She was extremely unbalanced, partly due to the large cochlear implant body worn processors that swung on either side of her body with each step she took. The progress she was making with receptive and expressive language and the simple fact that she was WALKING, made it easier to swallow the difficulties she had even though she fell every few feet.



Then you wake up one morning and notice a slight chill in the air. Change is coming once more...

Of all of the seasons, I think Autumn is the most beautiful. It is a time of reflection on what has worked best and what didn't work over the last few months. Is more therapy needed to reach another level? What other challenges have appeared now that the child is growing older? Schedules are rearranged to fit the needs. Reviewing past memories produce some that are as beautiful as the gold and orange leaves in the trees, while others remain green and dull. In Bella's case, her implants are checked in the Fall to ensure they are working properly and also reprogrammed to achieve the highest level of sound quality.



There is also another kind of reflection that sometimes happens as you review the previous months. Seeing another child the same age as my child with no disability has at times put a cold shiver up my spine, if only for a moment. It is difficult to see how easy the monkey bars can be for another little girl or how she doesn't struggle to hear her Mom call her in the loud, noisy playground filled with lots of noise.

Like the day warms up after a cool morning in Autumn, I push this chill away from my soul. Focusing on what my child can't do will not produce the confident child I desire. Yes, she has challenges, but it is my job to teach her how to work around them to the best of her ability and not dwell on them.

Then, before you know it, the winds have changed once more and the chill that was only lasting in the early morning has crept in to the whole day. Another major obstacle has been placed in your way. One that you were not expecting and you are not sure you will be able to handle. One cool February when Bella was two, we were told one of her implants had become infected and would need to be removed. It meant surgery to remove it and surgery a few months later to put it back in after the infection had been treated.

Again, it is time to take a deep breath and walk forward, no matter how slow. It is the forward progress that is important. Winter is back now, but Spring will be here soon...

Tonia resides in Chaska, Minnesota with her husband and three children. Last year she started a blog, www.rowefamilyadventures.blogspot.com. She writes about parenting her daughter with special needs, Isabella, as well as the many other parenting adventures she faces with her older children, Rebecca and Harrison.