

## Lessons From Ava March 2026



Ava Rayne McKee

Hello Friends and Family, I'd like to share these thoughts that came to me while quietly watching Ava as she slept.

I can only imagine what really goes through my 4-year-old Ava's mind as she ponders the day. Each activity, every verbal request from me, the smile and comments from a stranger at the local grocery store, the familiar embrace of her sisters, or the firm voice from her mother or father hoping to instill a sense of awareness of things that may cause her harm or danger. Ava is not bad at all; she doesn't have behavior issues. She is the sweetest child ever. However, there are a lot of things she does that take a lot of patience on my end. As I sit and ponder this I wonder; Am I doing what's best for her? Do I use the correct words to discipline her or correct her in the world as she sees it? You see Ava sees the world differently than most. She wears a constant smile, proving joy still comes in the smallest, stickiest packages. She loves people, but sometimes at a distance. She likes to re-buckle the top strap on her seatbelt AFTER I have unbuckled it – we don't move until she does that. Every load of clothes that comes out of the dryer is brought to the living room by both of us, never again will I do that alone. She loves her food but only one food item at a time – she doesn't like options. When we're at the grocery store buying big groceries, the employees have grown to know and love her so well that they know not to put any item next to her – she doesn't like that and usually it goes overboard to the floor if so. Anytime we come inside from running errands or taking a walk, as soon as we walk through the door, off goes the shoes, socks and pants, nothing comes before that and you better hope you aren't leaving again because redoing all that too soon is a fight I don't pick with her anymore. I'm the only one allowed to push the grocery cart or stroller. She guards those handles with her life convinced mom is the only one who can push either one. She went through a phase recently where she wasn't getting in the tub unless she could take her shirt off after she got in. I've come to learn it takes a lot of patience and understanding daily all while realizing we are walking this path together, and the beauty that comes with learning from one another. Believe me when I say the benefits far out-weigh the challenges. Ava is a sweet, lovable child who is extremely precious and special to our family, she just happens to have some special needs. You see, Ava has Down Syndrome and lives in a world we often can't quite imagine.

**Moral of the Story - The Lessons:** I'm learning alongside Ava as we make this journey. I'm beginning to understand that she thrives on predictability and control (seatbelt routine, laundry process, food one item at a time). For her, transitions are hard (leaving, coming home, getting dressed/undressed again). Sensory or spatial preferences matter (items near her in the cart, how clothes or routines happen). She connects with people, but on *her terms*. I've come to realize that it's more about preparation than correction and not so much about discipline as we understand it, but guidance and structure that provide the best outcomes for her. I hope you've enjoyed a brief glimpse at a 'day-in-the-life' with my sweet angel Ava.

March 21<sup>st</sup> is World Down Syndrome Day. 3/21 represents the three 21<sup>st</sup> chromosomes that result in Down Syndrome. So please say a prayer for these very special children and adults as well as the families and care givers that exercise patience and love on a daily basis as they do the best they can to help their loved ones survive and thrive in our so-called 'normal world'



*Sarah B. McKee*

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