

An excerpt from...

Remington Walls & Stephanie Walls

Home Plate

A True Story of Resilience

Note: The italicized inserts are Remington's words. The rest of this chapter is from Stephanie's perspective.

All rights reserved. Copyright © 2018 NOW SC Press

Chapter 4

The New Normal

Throughout all of this, we still had another son who needed our attention and devotion. We were often so focused on Remington and his illness that we sometimes neglected our older boy, Dalton. When you have one sick child, though, it's hard not to give him all your attention and worry. Our lives revolved around the EoE at first—around food and formula, and trying to find the best course of action for Rem.

The four of us used to do so many activities together, like going to the zoo, to the museum, or to Walt Disney World. But now, because of all the numerous medical appointments, we simply couldn't afford anything extra, which was also an adjustment for both boys. Mike and I both scheduled time to spend one-on-one with Dalton so he wouldn't feel excluded. His world had already changed when his younger brother came along, but now, with the constant worry and focus on the EoE, Dalton's world changed even more. At times we felt guilty about not finding the right balance between the two.

The biggest challenges, however, were found outside our home. A simple social gathering with other families became an ordeal. We were so far from a normal family that to be with friends around food was extremely difficult. I found I was becoming resentful every time someone expressed their sympathy or said they knew what Rem was going through because they couldn't eat when they had the flu or were on a strict diet or far from home. I simply smiled and nodded, while inside my heart was bleeding from the misery. I'd say the right things, but I'd be screaming to myself, *No, you really don't know what it's like to have a child who can't eat. You still attend your socials, holiday gatherings, and family get-togethers; and by the looks of you, you really don't have a clue what it's like to not eat. You look to me as if you know how to eat pretty well.* I began looking at people differently, especially people who were overweight. I became quite judgmental, not because I'm that kind of person but because I was hurting for my son and for what this had done to our family.

We needed to erect protective walls around us so that we could get through all the “firsts” during that first year. People mean well. I have complete understanding for all of those who tried to offer reassuring words and kind gestures, but in that first year it was almost impossible not to be resentful or angry. We were trying to navigate an alternate universe that was plopped inside our normal world.

People meant well, but sometimes said completely the wrong thing. One time when I went to pick Dalton up from his summer camp, one of the moms standing by me waiting for the kids to grab all of their gear, asked me which one of our boys went to the camp. I told her Dalton. She then said, “I didn't think the other one could go because he's not able to eat and that could be a problem.” Even though her words hurt me—because really, she was right—in that moment, I

realized if I allowed it to be a problem then it would be. I decided, then and there, to use the hurt to prove her and everyone else wrong. Sometimes it's the unkind things that chisel little bits and pieces of us away, but that little bit of chiseling sharpened my stone and made me stronger to face more ugliness along the way. It also fostered my determination to find a way around obstacles so Remington could participate in any activity or camp that he wanted to, such as traveling to the Dominican Republic and later England and Scotland. Still, there were rough days, not just for Remington, but for all of us.

“When I was little, I was confused and angry about my diagnosis. One morning, as I went into Sunday school class, my teacher at the time, Ms. Shamaine (my friend Cameren’s mom) bent down to greet me. “Hello, little Remington,” she said. Instead of greeting her back, I kicked her in the shin. I was wearing cowboy boots that morning and that sharp little kick caused her to almost double over in pain. My parents made me apologize, and I still feel bad about that morning, but it was a moment of frustration for a little boy who didn’t understand why his world had suddenly changed so much.”

Mike and I began drifting apart from each other as well. A child with an illness puts incredible pressure on a couple. Compound that with the fact both boys were young and the medical bills were enormous, our marriage began to suffer. A wonderful couple from our church invited us to attend a marriage conference with Dr. Gary Chapman, the author of *The Five Love Languages*. I was worried about leaving Remington with my parents for the weekend, but I also knew Mike and I needed to get away. It turned out to be the best decision ever.

When Dr. Chapman took a break, he offered to speak individually with couples for a brief amount of time. I jumped in that line and was later so glad I did!

It was a rather small conference and, thankfully, it didn't take much time for me to make my way to him to share our situation. It all poured out—the frustration, the meals in our bedroom, the stress. Dr. Chapman listened and then advised the way we were treating Remington was causing our family to revolve around him. We were actually making Remington the center of our existence, neglecting our older son, Dalton, as well as our marriage. Wow! He was so right. The very thing that had kept us together was our family time, our bond around the plate at the dinner table. That was our nucleus and where we caught up with one another and built our family's foundation. We lost all of that when Remington was diagnosed and food became the enemy.

Dr. Chapman said that, even though we meant well, we were destroying our family and were well on our way to destroying our marriage. He recommended starting to change that by gathering around the table and having dinner together again as a family. He stressed that we must teach Remington that, while his disease is unfortunate, life is not always fair. He told us to emphasize that Rem has his form of nutrition now and we must have ours. He also suggested we get used to eating as a family again by adding a conversation starter where each person took a turn answering a question. That way, the focus wasn't on our food but on each other and our family conversation around the dinner table.

I couldn't wait to get home to the boys and try this out. It wasn't as easy as it sounded, but we did

return to sitting at the table again as a family. We chose to avoid snack type foods and dessert treats and decided to only cook foods that would nourish our bodies. At dinner time, we would gather around the table, say grace, and begin our questions with a conversation starter. Remington understood that he wasn't to get up from the table until he had finished his shake for dinner. Sometimes, he would find himself seated at the table a bit longer than anyone else but he quickly learned that his need for nutrition was a non-negotiable. Of course, there were the occasional fits of screaming and pushing his shake box out of his reach to avoid drinking it, but day by day—just as God promised—our lives became a bit more hopeful.

Our very first Thanksgiving with Remington in his foodless world, we decided to go camping. We had camped regularly since the boys were babies and we loved being able to just get away from it all. We originally spent the Thanksgiving holidays around a table with family and tons of food. However, that year Remington had just been removed from foods only a month before and we were still struggling as a family, so we thought it best to venture out. It turned out to be one of our best decisions. We focused on our family time, playing board games and card games, or simply sitting by the campfire talking and sharing memories. Remington was learning to reach for that shake when he got hungry. That Thanksgiving we were not feeling so thankful because we were still coping with our pain and Remington's losses. That Thanksgiving we didn't have a big celebratory meal either. We simply ate ham sandwiches while we played cornhole and it turned out to be one of our best holidays ever.

“After that first Thanksgiving when we went camping, we planned our hospital trips to Cincinnati around Thanksgiving break so I wouldn't miss school. We stayed at my cousin's home in Columbus, which was a lot of fun because I've always been close with all my family up there, especially my cousin Emma. She's only a year and a half older than me and has always been more of a sister than a cousin.

Every Thanksgiving, their family has an annual ritual: they go up to the local high school football field and kick field goals. Since we're usually up there, we get to tag along and join in. Later, when I learned to sit at the dinner table with my shakes, we began joining them at their holiday meal, too.

Ohio often gets snow in November and we Florida boys loved playing in the snow. One time, Emma, Dalton and I made a snowman in her front yard, using sticks for arms. We were so proud of our creation. As we were telling our families to come look at our snowman, Emma's dog Duchess ran over, grabbed the snowman's stick arm and ran around the yard. We all began chasing after Duchess in the snow to get the snowman's arm back. Everyone was laughing and it

”

was such a wonderful, normal, family moment.

Eventually, we went back to cooking in the kitchen. Sometimes, Remington would come up and ask to smell the food. Once I had the foods on the plate, he would actually breathe in each food item and he would say, “I remember what that tastes like.” Those are the knot-forming-in-your-throat moments. Those times when, as a parent, you're trying to be strong so your child doesn't see your own weakness. Or your tears.

At times, Dalton felt guilty for being able to eat. I struggled when it came to grocery shopping.

Do I buy the Cheez-It crackers for Dalton? I was afraid Remington would try to eat them too. The same thing for the cereal or the lunchmeat or the cheese. How was I supposed to shop for groceries anymore? I found myself walking the aisles and seeing other families shopping together. How would we ever do that now?

Then came the challenge of dining out. Before the diagnosis, good report cards meant the boys could choose a restaurant for a celebratory meal. Dalton's favorite place to go was Red Lobster. His report card came home and it was fantastic. He was so excited to go out to his favorite restaurant. Mike and I debated but ultimately decided we should keep the tradition. We packed a lunch box for Remington and set off to Red Lobster. This was the first time we had dined out since Rem's diagnosis. It was so hard. Tears came to my eyes just looking at the menu, knowing Rem wouldn't be able to order off a menu like that, maybe ever again.

I brought our conversation starter flip chart and placed it on the table. We ordered our food and began sharing about our day. Dalton was so excited, proud of his grades and of this moment about him. We ate our meals and then Dalton asked if he could have dessert. For a normal family, that's an easy answer—but for us, dessert was anything but easy. When Dalton's chocolate cake came out with whipped cream and a cherry, I saw the look on Rem's face that said plainly, I want some. We tried to focus on the conversation starter, but we all watched Dalton devour his dessert and silently wished for just a bite of that chocolate gooey-ness.

The very first birthday party we had for Remington in his foodless world was when he turned five. We decided to have the party at the bowling alley so the kids could keep busy and not focus so much on eating. Instead of having pizza, chips, soda, and cake we rented a snow cone machine and brought it to the bowling alley. When it came time to sing happy birthday, we gave Rem a snow cone with a candle in it.

I remember hearing kids ask where the cake was and seeing some parents huddled together inquiring about the food. For us, this was our new normal. For them, this was a moment they shared in Remington's new world. That first public birthday celebration hit Mike and I hard. We both choked up when kids sang "Happy Birthday" to Rem. It was a tough, heart-wrenching moment for us. Some of the parents who hadn't known about Remington's disease until that moment were sympathetic and emotional.

We decided to let Remington decide what we'd have for his birthday celebrations. If he didn't want food then we wouldn't have food. It gave him a small measure of control over something other kids took for granted and allowed others a glimpse into his world.

As each birthday passed, we discovered we'd become more active and creative in deciding where we held his parties. One birthday was spent on a pirate cruise, one playing laser tag, and yet another at an airsoft field. Even though Rem's birthday is in January and it might be a bit cold, each birthday's dessert was a snow cone.

We learned to celebrate without food. We learned to focus on what was important, not on a cake or ice cream. We no longer gathered around the table for a formal celebratory meal. We left food out on the table and when the guests were hungry they'd grab a bite while Rem drank his shake. Then off they'd go again, playing manhunt in the woods or swimming in the pool. It got easier, but still we hurt for our child, who was left out of a rite of passage.

When Rem was invited to birthday parties, he would go to the ones that involved some type of activity or outing like tubing, airsoft, or going to the movies, and he'd bring his lunch box filled with shakes. As time went on, he began to be comfortable around food and comfortable with his disease.

We might not have been sitting down to eat cake or passing the peas to Rem, but our plates were full. Full of first time experiences like these that really caused us to hurt in our hearts and made lumps form in our throats from holding back the tears. Mike and I would watch Rem, a hundred unspoken questions between us.

“I remember my mom and dad taking turns to come to my school for class parties and going with me when my friends had birthday parties. The first class party was the hardest and most painful. During all the excitement and fuss over a cupcake, candy, and punch, my mom took my hand and led me to the bookshelf so that I could read with her. What kid wants to read a book instead of eating a cupcake or candy? My mom could have taken me home instead of making me sit there, but my parents were tough on me because they knew I needed to learn how to navigate through the many food situations that I would have to face.

My mom also sent in non-food treats to school, like pencils, baseball cards, erasers, sticker packs, Matchbox cars, and little bouncy balls so the teacher could hand those out as treats/rewards. Mom also made up little goodie bags for me when she knew there was a birthday party. That way, I could be handed that one instead of the one filled with candy and I wouldn't feel excluded.

Then there was Halloween, Thanksgiving, and Christmas. For Halloween, my parents decided to pay me a quarter for each piece of candy I got. Then we'd count it and they would take me to the store so I could buy something. Dalton loved this plan because I would give him all of my candy after we counted it.

At a Christmas party at school, my dad took time off of work to join me. The class was decorating cookies. I'd decorate mine and my dad immediately ate it. As much as possible, my parents tried to keep my life normal. I'm not saying it wasn't hard to not eat those cookies, but my parents did their best to ease that pain and keep me from feeling “different”.”

What did the future hold? What would life be like for Rem? What will it be like when he starts dating? What will others think?

Questions aside, we were full of faith; secure in the knowledge that God doesn't give us any more than we can handle and only enough to challenge us so we become stronger. When our strength wavered, we reached out to God to shore us up.

Most of all, though, our family was full of love and a hope that continues to keep us fighting for life and a cure. That hope keeps us going, ready for the days to come and whatever challenges they might hold.