

## Chapter 1 - "The Sky is Falling."

### PART 1?

Help! Help! The sky is falling!

"Are you sure you're okay?" Dr. Veale tilted her head to one side, eyebrows furrowed, observing me and my unusual response, or, lack thereof. I'm sure she expected anger, sobbing, and a multitude of questions.

"I'm fine," I said.

"That's a lot to take in," she added, before she looked back down at her papers and signed her name to them.

She didn't believe me, I could tell. She was expecting a reaction of some kind; crying, shouting, anger. She looked up and stared at me, giving me a moment to digest the shocking information that I had just been given. Bracing herself.

Facing her in my plastic chair, hands folded on my lap, I nodded my head, slowly. She probably thought that I hadn't heard right.

"I'm fine, really. I'm just glad to finally have an answer," I managed. Had my voice started to catch in my throat?

It was true. Mostly. I was happy to have an answer and finally have a name for it. It didn't matter what it was called. If he had it, he had it. At least I knew what was to blame.

I was fine in the sense that I was not overly shocked to hear the diagnosis confirmed and spoken aloud. All the traits my son had been exhibiting for the past nine months were synonymous with a diagnosis of autism. The incessant hand flapping, lack of eye contact, and failure to acknowledge his own name had alerted my family physician, Dr. Colleen Maythem, that something was awry.

So here it was, my son, Darcy, two years and ten months old, was autistic.

The label that had inspired fear and worry since its suggestion in Dr. Maythem's office months ago, was now forever attached to the little boy who stood at the table in the centre of the room, lining up toy cars.

I could see him in my peripheral vision performing his solo act of play that never involved anyone else, lost in his own little world.

"Have you ever known anyone who has autism?," Dr. Veale was asking me.

I began shaking my head and looked at the floor, "no." It was hard to look into her eyes now. I noticed a box of Kleenex on the desk, within arms reach.

The only person I knew who had autism was Rainman. I had watched the movie, starring Dustin Hoffman, for the first time as a teenager who was only looking for entertainment value. The second time I watched it, just a few months prior to this appointment, I could have cared

less about entertainment. I scrutinized the characters on the screen. Was this what I could expect? I had become more watchful and skeptical of Darcy's every move and sound. Was it typical or atypical? If I tried really hard and worked with Darcy every day could I alter this pending diagnosis? Could I stop this from happening? Something, all those months back, had begun to gnaw at the pit of my stomach.

"I am going to put together some pamphlets and information for you to take home and read," Dr. Veale was saying again. "You'll want to contact professionals in your area as soon as possible to start intensive behavioural therapies. Remember that the first five years of age are the most crucial to a child's development."

First five years. Crucial. Of course I knew those years were crucial. The Canadian Broadcasting Corporation drilled that into my head every time their commercial for Sesame Street played across the television screen. I sat up straighter in my chair and did the math in my head. My heart beat faster and my hands felt clammy. Darcy was nearing his third birthday. Five minus three equals two. Two years left of those first crucial five. I was already behind. Oh my God! I was already *years* behind. It felt like the starting gun had been fired and I wasn't even at the starting line yet while everyone else had sprinted off, leaving me in the dust with this ball and chain of autism around my ankle. I wasn't conditioned for this. How does one prepare for this sort of race? A race against time. A race to fix my son.

"Wait," I said, registering the rest of her sentence about contact with professionals. "I have to find these professionals myself? You mean, there's no referral to services?"

Where was I supposed to begin, especially if time was of the essence? There was no time to waste.

"No, I'm sorry. I will send my assessment and findings back to your family doctor today but you and your husband will have to choose what services and therapies you think are best or that fit your budget. It's different from province to province as well. At least back home in British Columbia you are entitled to way more money than you would receive for this here in Alberta."

That was true. The provincial government of B.C. Canada, under the Ministry of Children and Family Development, gave large amounts of funding to families with children under the age of six so that they could pay therapists and behaviour interventionists to work with their young children. For this reason autism was a label that doctors and specialists were wary of giving out and parents were desperate to get.

"So, while he is on the autism spectrum, the official diagnosis that I am giving Darcy today is PDD-NOS. It's an acronym for Pervasive Developmental Disorder - Not Otherwise Specified because Darcy is still quite young and I couldn't be confident of a few of the criteria needed to give a definitive diagnosis of autism at this point. Okay?" Dr. Veale began to stand. "I am just going to step out and grab those pamphlets and information for you."

She closed the door as she stepped out. Darcy and I were left in the large room where toys and puzzles were used by professionals to observe and assess their young patients. Darcy rummaged through a bin of toys at the other end of the room, searching for another vehicle to add to the long parade of vehicles he'd been intent on lining up. A wand-like tool still lay on the table where Dr. Veale and I had been sitting. She'd held the wand with its ultraviolet light over Darcy's skin and searched for birthmarks earlier in the appointment. Birthmarks discovered in this way may have indicated a condition called Tuberous Sclerosis which could have been the reason for Darcy's diagnosis. No birthmarks had been found though. Blood had been drawn when we'd first arrived to meet Dr. Veale today and because of that Fragile X Syndrome had also been ruled out. So what had caused this? Why was this happening to my baby?

"Okay," Dr. Veale said as she stepped back into the room, the door closing behind her. "I photo copied some pages from the DSM to give you more information."

The pile of papers she handed me looked like it could have been a manuscript for a small novel. I stared at the pile of papers in my lap. I could tell that this was not going to read like some fairy tale.

"There are support groups here in the city, depending on what you can find in your area, it may be worthwhile to reach out to these groups." She paused, her eyes settling kindly on me again. "I'm sorry. Did you come all by yourself today?"

It took a moment to find my voice again.

"No, my Mom and Dad drove me in today because my fiancé is working away from home. We left Darcy's older brother, Dawson, with my in-laws. We're staying in a hotel tonight. It was a four hour drive this morning."

"Okay, well, do you have any questions for me before you go?"

I shook my head slowly as I rose on weary legs from my chair.

"No, I mean, I can't think of anything right now." I stuffed the papers into the diaper bag that I was in the habit of carrying around like a purse. Darcy was still not entirely toilet trained. He had a lot of accidents and I always needed to be prepared. Plus, because of his erratic behaviour and squealing, I needed to pack a lot of bribes and toys, books, that I could use to distract and occupy him.

"Okay Darcy, it's time to go." I slung the strap of the bag over my shoulder and grabbed my purse.

Darcy quickly grabbed his own cars that we had brought along with us and held them tight against his chest and under his chin. His soft, pudgy fingers found mine and I led him back out to where my parents were waiting.

"So?" My Mom asked as our eyes met upon entering the waiting area.

"Yah, he has autism."

I'd said it. Not very loudly, but I'd said it. That word. I swallowed a large lump in my throat and my eyes began to burn. My Dad walked over from where he'd been standing, reading a poster on the wall.

My Mom nodded her understanding and stood up to put her coat on. "Did she give you any information?"

"Yah," I gestured to the diaper bag, "I've got a lot of paperwork we can look at once we get to the hotel."

"Okay, Darcy," my Dad sighed, helping Darcy with his cars, "Let's go push the button for the elevator."

Darcy didn't say anything but after he'd dropped his cars into Grandpa's hands he half skipped and half ran to the elevator where he slapped excitedly at the button on the wall.

We all stood quietly before the metal doors, not saying anything, listening to the inner workings of the elevator drawing near. All but Darcy could feel the heaviness that descends upon one's shoulders when bad news has been delivered. The boisterous quartet that had entered the building just hours earlier, left quietly, somberly.