

# Puzzles

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Sixty years ago, a scientific discovery was made.

A name was put on a condition that was previously lumped in with mental retardation, brain damage, or schizophrenia. In 1911, the name was first put into existence. By 1944, it was recognized that people with this disorder were lacking socially and emotionally. In the 1970s, great strides were made in the area of therapies for children and adults alike. Many years of research and treatment options and parents' tears and teachers' frustrations led to an organized system of testing, diagnosis, and therapies that now help the 1 in 59 children diagnosed each year in the United States with autism spectrum disorder.

I have never liked strategy games or brain teasers. The two nails twisted together that have only one way of separating, or the game Battleship, or the dreaded Rubik's Cube. At a games' shop a few years ago, I bought a puzzle that was two small metal elk heads with their horns intertwined. The only thing a person had to do was find the one way to separate them. I spent hours, hours, trying to figure out how to separate the two heavy sets of horns from each other. In my frustration, around the third hour of trying to physically pry them apart, I threw them across the room because I believed I would never find the solution. When my husband came home that evening, he looked at it once, said, "Oh, I see now," and made two quick moves that separated the antlers like they were never meant to be together in the first place. I was furious.

When Barrett was born, he was beautiful.

Of course, I'm biased. He's my first born, my first boy. He was an unexpected baby, as I was

finishing college and Travis and I wanted to be married for a few years before having kids. I cried when I took the test. How can I finish college? How can I start a career? How can we travel now? Self-pity surrounded me. I would tell people, "We're so excited!" even though it wasn't the truth. The truth was that I was terrified of being a parent, terrified of the dependency of a child, terrified of the thought of giving up my own dreams for motherhood. As they placed him on my chest, I felt the weight of all the new responsibility that I would have to uphold. I remember thinking, stop being so selfish, there are women in this world who can't have children. I thought of my sister. I was 22, immature, and frightened. This new little puzzle placed on my chest was the most daunting thing I had ever seen. But I could not deny it: He was mine.

Some children show signs of autism as early as six months old. They may not smile as warmly or have engaging expressions. Other babies may avoid eye contact completely. By nine months old, an autistic child might stop mimicking sounds or showing facial expressions. When the child is one, babbling can stop, interactions with people can halt, and they may not even respond to their name.

When Barrett was one, he said "trato."

Over his first year, I was a poor mother. Post-partum depression hit me like a train, and there were times that I truly believed my life was over. Barrett and I were alone for at least 12 hours every day, and since we live about 20 miles from any large town, we rarely left the house. Travis was only a mile away at the farm, but I didn't want to bother him with my sadness. He got enough of that when he got home at night. But Barrett was a happy, normal baby. Friends, family, and church members would look at us and say, "Wow, he's so well-behaved," or, "what a perfect little

baby!" Besides a bit of reflux, Barrett really was developing well. He laughed, he hugged, and he ate whatever we put in front of him. To us, it seemed that this puzzle would be easily solved; there were plenty of strategy books out there on parenting, and many other seasoned parents gave us tips and tricks whenever we hit a roadblock with our son. When Barrett was one, his favorite word was "tractor," although he said it like "trato." Every time his dad or grandpas would drive a tractor by or let him ride in one, he would excitedly say, "Trato! Trato! Trato!"

That was the last word he said for almost three years.

In the period between one and two years old, children with autism lose much, if not all, of their communication skills. Many develop obsessive, repetitious behavior, such as making the same guttural sound over and over or flapping their hands. In most cases, a child will refuse to make eye contact and prefer solitude to being with their peers. Minor changes in a schedule can lead to meltdowns and hypersensitivity to lights, sounds, and textures can be prevalent.

When Barrett turned two, I went into denial.

In the spring of his second year, something changed in Barrett. Looking back, I don't know if I can pinpoint the exact instance that I noticed this change. He stopped chattering to himself, he would watch Baby Einstein obsessively, and, the most obvious, he wouldn't look anyone in the eye. When we got into any vehicle, I didn't understand why he would make the same low growling noise repeatedly. It made travelling almost unbearable, as he never stopped making the noise until we arrived at wherever we were going. At the time, I knew nothing of developmental delays, so I just thought that he would come around. It seemed that my puzzle was evolving. I was now playing

a strategy game where I didn't know who I was playing against, or what the rules were. Few people could give us advice on what to do, and one of the most common comments was, "Oh, I'm sure it's just a phase."

One evening, I put Barrett in my lap and tried to force him to look at me. At this point, he avoided any eye contact with people. He cried and screamed in frustration that I wouldn't let him go, and I held his face tightly in my hands. I said, "Look at me, Barrett! Look at Mom!" in the friendliest voice I could muster. It wasn't long before that loving mom-voice turned into weak sobs as he kicked me and screamed, trying to get away. "Look at me, Barrett! Please, please look at me!" For twenty minutes, my son fought me. For twenty minutes, I tried to convince myself that this was normal.

Why are all the other children at church not struggling? What did I do wrong with my son? Why is it me, the one who hates puzzles and strategy, who was given the hardest evolving puzzle of them all?

At his 18-month check-up, I was offended that my doctor referred him to the Birth to Three program after he couldn't point out where his tummy and mouth were. "Nothing is wrong with him," I remember my dad saying. So I didn't follow through with the Birth to Three contact. Instead, we contacted hearing specialists to be sure he wasn't suffering from repeat ear infections. At that point, I was willing to investigate any condition or contact any specialist that would tell us that there was a simple solution to this puzzle that I just wasn't seeing. The first doctor, an ear doctor who specialized in hearing aids for the elderly, told us that he was probably just having ear infections, and that was what was causing his delay in speech. Elated, I messaged my family

members to let them know that we had finally found the reason to Barrett's delays. For me, it was the first time that I felt hopeful about my son's situation.

After two weeks of ear infection treatment, I so desperately wanted to believe that Barrett would come out of whatever phase he was going through. At the advice of our family doctor, and with much apprehension, we did a follow-up appointment in Sioux Falls with one of the top ear, nose, and throat specialists in the state. That day, Barrett was especially challenging; he would not look in my direction, would not listen when I called his name, and he would try to hurl himself to the ground because he was tired. As he took the tests before he saw the doctor, I found myself hoping and praying that they would find something wrong with his hearing. If they found something wrong there, maybe we could fix it easily. If it was only the connection between his ears and his brain that was flawed, maybe one surgery could solve his problems. As the tests were completed, the verdict was in: nothing was wrong with his hearing. When we finally went up to Dr. DeSautel's office, he quickly checked the results of our visit. He looked at Barrett, who was fussing wildly in my mother's arms, and I could tell he was going to give me an answer that I did not want to hear. He was the first one to say the one phrase that I was denying existed: Have you looked into autism?

I felt the heat in my cheeks. Tears quickly made their way to my eyes. I felt like a two-year-old who was scolded for stealing a cookie.

I choked on my answer.

"We are not ignorant of autism," I said in complete ignorance. I tried to hide the fact that I felt like I was trying to swallow a pill four times the size of my esophagus, but my face spoke for my emotions. Dr. DeSautel was kind, but at the

time I looked at him as if he were the devil himself. I wanted to get out of that office as swiftly as my feet would take me.

My mom carried Barrett out of the building for me. At 40 pounds, he was no light load. But I couldn't handle it. How dare he. How dare he suggest that my son has a condition that isn't fixable. How dare he suggest that to me. I shouted at my mother when we got in the car; she was the unfortunate recipient of my ignorant rage.

How dare he.

Between ages one and two, I denied and denied and denied.

What does one do when given a puzzle that can't be solved? Or a strategy game with no instructions?

I cried. A lot.

He flapped his hands a lot. I would take his hands, softly most times, and put them down at his sides to get him to stop. When I would go to Coborns, church members or neighbors would delightfully ask him his name, to which I would quickly reply, "He doesn't talk yet." But I couldn't explain when he didn't follow directions, didn't look at people when they talked, or didn't stop moving no matter what he was doing. So I avoided people I knew in public. Wore a hat to cover my eyes. Barrett couldn't tell me he had to go to the bathroom, so he would cry and fuss as I picked out flour and cocoa powder from the baking section. He wet himself and cried with even more frustration because he was so uncomfortable. I pushed my cart passed fellow shoppers. I remember an older woman walked by me as I headed to the dairy section: Why aren't you taking him out of here? Like I could hear her thoughts. I wanted to look at her in the eyes and say, "this is the fourth time this month he's done this in public. I will handle it, thank you." But I didn't. I gave my

usual "I'm sorry" smile and worried expression as I sailed past her, Barrett in tow. I can still see the other shoppers as they glanced over at this sobbing child in soaked jeans and this mother with red eyes.

When he turned two, I finally called the Birth to Three director in our area to try and get him some help. I wasn't seeing any sort of improvement, and I knew that I couldn't live my entire life in denial that something was wrong. Seeing the other kids his age talk to their parents, form relationships with their peers, and show their imaginative thought processes was heart-breaking. My son couldn't even look me in the eye.

One morning, as I tried to clean my living room for the third time in a period of three hours, I had had enough. Every time I put something away, Barrett would immediately take it down. When I put the pillows back on the couch, he screamed and tore them off. When I turned my back, he was in a cupboard pulling out the DVDs and scattering them all over the floor, being sure to step on and break every one that he could. I had had enough. I screamed, "Will you never be content?!" and chased him to his bedroom in my anger.

I threw the antlers across the room.

The small boy looked at his mother in sheer terror. I could see what he was thinking:

What did I do?

I ripped his shorts down and spanked his bare bottom. I spanked him hard. Three times my hand hit his rear end, the hard smack causing the red welt almost immediately. I stood him up in front of me. The disgust in myself did not take long to settle in:

What have I done?

Here was my boy, my son, who had no idea why his mother chased him and spanked him. I sobbed as I clutched his little body close to mine. "I'm sorry, I'm sorry, I'm so, so sorry. I love you so

much" He was confused. He was scared. He tried desperately to release my grip on him. I let him go. For a half an hour, I sat on the floor of his room and sobbed. I sobbed for what I had just done, I sobbed for the situation that I was in as a mother. I grieved over the life I would never have. I cried for my son who did not understand what just happened.

As children with autism grow older, a new set of challenges usually presents itself. Many children will tend to run away from their parent or caregiver and not respond to their name. They may not understand simple directions or understand that stoves can be hot or the top of the playset can't be jumped off of. Food aversions and allergies are common, and children with autism are "eight times more likely to have a chronic gastrointestinal disorder than other children."

When Barrett turned three, I knew.

I knew it was time. I had been in denial that Barrett could have autism, but the signs were so obvious that I could ignore them no longer. He avoided most of the food that we put in front of him and even went through a period in which he would only eat five "safe" foods: bread, hot dogs, chicken strips, chips, and macaroni and cheese. With this diet, he would have constant stomach aches. With no way of communicating that he was in pain, he would flail his body around, sprint through the house and hurl himself on the couch repeatedly, or, the worst of them, scream at the top of his lungs. My strategies were poor in dealing with this; again, I found myself without instructions on how to better feed my child, who would gag at the sight of any vegetable.

In the summer after he turned three, the electrical company was taking out our telephone poles and replacing them with an underground line. The line was marked with little red flags about every

six feet or so. Barrett adored those flags. When we would walk outside, he would carefully collect them all and carry them around until I made him put them back where they belonged. One morning, around 5:30, Barrett decided that he wanted to go and get the flags. He opened the garage door and wandered outside, collecting the little red flags. I woke with a start, as usually he crawls into bed with us at 6:00 every morning.

“Where is Barrett?” I asked nervously.

Travis and I searched the house for him: in the back closet where the games are hidden, in the basement where he liked to jump on the beds, in the car where he would like to sit in anticipation of a ride. And that’s when we spotted him. Across our gravel road, there he was, flags in hand. And here came our neighbors in their red suburban. We called to Barrett as we ran towards him, but it was like he was deaf to our words. He was so close to the road, and if we hadn’t waived frantically at Bud and Gail to stop, they may have never seen the little boy with the red flags. And he would’ve never seen them.

We had his first IEP meeting during the school year, and I met with his speech therapist, early childhood special education teacher, and our superintendent. They expressed their concerns for Barrett, but also discussed his progress. In the year and half that he had been working with this small group of educators, he started taking directions, humming tunes, and was even making eye contact with people. At the end of the meeting, the superintendent left, and I let go.

I was ready to get Barrett officially tested for autism. I knew that I couldn’t put this off any longer, as my son’s future was at stake. This was no longer about me and my selfish desires. This was about my son who needed help that I could not give him.

When I told my parents, my mom cried. Her concerns, as always, were for Barrett’s future. “Will he be able to go to college? Will he be able to buy a house someday?”

I couldn’t answer her. All that came to my mind was let’s get through today first.

Barrett has autism.

On January 11, 2019, Barrett was officially diagnosed with autism spectrum disorder. There were no tears and no overwhelming emotions. The only thing I remember feeling was relief. As Travis and I went over the paperwork, we didn’t look at where he was failing, but we were able to see the strides that he was making. Only three months before his diagnosis, he was able to say, SAY, the entire ABCs. He started giving kisses and hugs to the people he knew well. He was recognizing faces and items and naming them. Our son had come so far and is still making improvements every day. We were able to accept this outcome and move forward, even though I lived so much of his life in denial.

Our puzzle keeps evolving, keeps shifting, keeps changing. I can’t stop the constant metamorphosis taking place in my son’s behaviors. But here is where I must adapt as a parent. It doesn’t matter that I don’t like strategy games, because I am playing one of the hardest strategy games in life: parenting a special needs child. I can’t quit playing, I can’t throw the antlers across the room in frustration, I can’t “skip a turn” in caring for my son.

Our son has autism. And he is beautiful.

There are still days that I wonder what his future will look like. Right now, he loves tractors and dinosaurs, he can name forty or more objects on his own (with no prompting), and he will follow simple directions easily. His teachers believe he is making great progress, and every day he surprises

us with something new. The other day, he showed us that he has imagination by pretending to eat a piece of plastic chicken, which is uncommon in children with autism. Barrett can interact with his peers, even though he still doesn't grasp the concept of sharing and waiting ones turn. With all this progress, I still worry about the years to come. What if he gets worse? What if he starts hurting himself? What if he never "comes out of it" like my family wants so desperately to believe?

My husband often tells me, "You have to have hope in this life, Leah. Hope is the only thing that will get you through." Sometimes hearing him say this makes me furious, but sometimes it makes me want to fall to my knees and cry. I had been hopeless for so long that it felt like I'd never crawl out of this pit of anguish. But every day I am reminded of how far my little boy has come in his short life. Barrett can repeat words, he loves physical contact, he can look me in the eye. I am thankful for that.

He is happy.

This year, Barrett is in preschool.

He sees his class of 10 other 4-year-olds two days a week, and we have been fortunate to have a group of kids that don't tease him when he doesn't do what they're doing. They ask him to join them when they play and don't ask why he leaves the room for his therapies. I even heard a story where one of his female classmates said that he was her boyfriend. Right now, Barrett wouldn't understand if someone was teasing him for being different than the rest of his peers, but as he grows, I worry about what his schoolmates will say about him. I want to believe that they will be kind to him, still invite him to play, and not make a big deal about him leaving the room when he has to go to his therapies. His hardships are only beginning in this life. But I am not hopeless anymore.

He likes to do puzzles.