

Moments after giving birth to their first child, Lisa and Steve Brown are devastated to learn that even the doctors didn't know his prognosis, much less how to explain it to them. Their newborn son, Logan, looked profoundly different.

Changing Faces: A Journey of Hope and Perseverance
By Lisa D. Brown

Order the book from the publisher BookLocker.com

<https://www.booklocker.com/p/books/12362.html?s=pdf>

**or from your favorite neighborhood
or online bookstore.**

Changing Faces

A JOURNEY OF HOPE AND PERSEVERANCE



LISA D. BROWN

Copyright © 2022 Lisa D. Brown

Print ISBN: 979-8-88531-074-1

Ebook ISBN: 979-8-88531-075-8

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, recording or otherwise, without the prior written permission of the author.

Scripture quotations are from The ESV* Bible (The Holy Bible, English Standard Version*), copyright © 2001 by Crossway, a publishing ministry of Good News Publishers. Used by permission. All rights reserved.

Full Cover and About the Author images by Monkey House Photography.

Published by Abuzz Press, Trenton, Georgia.

Printed on acid-free paper.

Abuzz Press
2022

First Edition

Library of Congress Cataloging in Publication Data

Brown, Lisa D.

Changing Faces: A Journey of Hope and Perseverance by Lisa D. Brown

Library of Congress Control Number: 2022902599

Contents

Chapter 1: Mayday! Mayday!	1
Chapter 2: Expect the Unexpected	3
Chapter 3: This Wasn't Supposed to Happen.....	13
Chapter 4: Diagnosis Revealed	21
Chapter 5: Brace For Impact	39
Chapter 6: Back Under Construction	57
Chapter 7: A Baby Sea Turtle Has Hatched!.....	71
Chapter 8: Happy First Birthday to Logan!.....	85
Chapter 9: Alien Face.....	95
Chapter 10: The Elephant in the Room	105
Chapter 11: Super Sibling, On the Way!.....	111
Chapter 12: Time Marches On	125
Chapter 13: Change Is A-Comin'	133
Chapter 14: Bittersweet Halloween.....	157
Chapter 15: School Daze, More Diagnoses, and Brotherly Shenanigans	165
Chapter 16: The Doozy	177
Chapter 17: Face to Face	191
Chapter 18: Independence Day - Freedom Has New Meaning.....	217
Chapter 19: Time to Meet Some People Like Us.....	227
Chapter 20: Conviction of the Heart	233
Chapter 21: Graduation 2020	251
Chapter 22: Perspectives	265
Chapter 23: One Day at a Time, Sweet Jesus.....	275

Acknowledgements.....	293
Notes	297
Information & Resources.....	303

Chapter 1

Mayday! Mayday!

“Courage is not simply one of the virtues, but the form of every virtue at the testing point.”

~ C.S. Lewis

January 18, 2002, 6:05 p.m.

The woman turned off the video camera. Tears welled in her eyes as she gently laid it down on my bed and walked out of the hospital room. The silence was suffocating, until my first newborn broke the sound barrier as he screamed at the world he had entered.

“6:05. You did it,” uttered my husband with hesitation and confusion in his voice. Plans changed.

I looked at everyone, trying to figure out what happened. They looked around me with their reflected fear, masked with silence to the questions from my eyes. *Why isn't anyone saying anything? What happened?* Words finally formed, so I asked: “What's wrong? Is he okay?”

The room went dark. I was no longer in control. *Wait, did I even have control in the first place?* I was now aware of how sterile the room was. The fluorescent light above my head buzzed. The sudden urgency of the stifled medical staff in their muted scrubs and the silence of the other humans in the room swirled around me like a vortex.

This was the happiest and hardest day of my life. The cliché became my perfect juxtaposition. Nothing could prepare me for what life was about to be.

Chapter 2

Expect the Unexpected

“Never be afraid to trust an unknown future to a known God.”

~ Corrie Ten Boom

Perfection. Isn't it the American dream? We want it all. We take necessary steps and make preparations for our lives with visions of what it will all look like for our future. For me, it was the house with a big backyard, two kids, and a dog, while it all works out perfectly according to our own dreams and plans.

I always wanted to be a mother, even as early as seven years old. I knew I would someday want to have a baby. Growing up, my little sister and I played house. We would stuff a pillow underneath our shirts and pretend we were moms-to-be. One year I got a Baby Alive for Christmas, which was the best present ever! I couldn't wait to hold it, feed it the little mush food that came with the doll, and even change its diaper. It's weird when you think about it. You put fake food into this plastic baby doll, then it would run through and out the other end. The gross stuff coming out of the baby, however, didn't matter to me. I carried it around anyway like it was real.

I imagined what the day would be like when my dream to have a baby became a reality. If it was a boy, he would look like his daddy and grow up playing sports in the backyard. If it was a girl, then she would have her daddy's eyes and my locks of curls. Subsequently, she wouldn't have to fret over her hair too much. Perhaps she would even love running track, like me.

After Steve and I dated a few months, we talked about things we wanted in life. "What do you dream of in life? Do you ever think about having children?" I asked.

"Yeah, I do want to have kids someday, a house of our own, and maybe find a church to go to," he replied sheepishly.

I was comforted and felt we were on the same page. "Good, I want those things too," I rejoiced.

January 18, 2002, 8:00 a.m.

Steve and I walked into the hospital to check-in. Inquietude veiled my demeanor for a moment, but I couldn't explain why. I chalked it up to nerves of giving birth for the first time and some fear of pain. Words of a labor instructor from a birthing class Steve and I attended three months prior, resounded in my ear, "expect the unexpected... expect the unexpected...expect the unexpected." She said this *three* times as she walked around the room while we were all on the floor pretending to give birth. I looked across the room where other pregnant women sat. It was so awkward I couldn't keep from giggling. We were all in a circle facing each other as we stared with uncomfortable gazes. It was a comical sight as the husbands sat behind the wives. I'm sure they all felt as awkward as we did.

Everyone breathed mantras of *he-he*, and *ho-ho*. I giggled more, which I knew embarrassed Steve because the rule was to be quiet. He was such a rule follower. The awkward silence made it even funnier to me.

After she finished her chant of redundant advice, I thought to myself *Lady, we get the picture*. For a split second, I wondered if this message was for me. I brushed it off, pretty much saying, "meh." I never told anyone of this feeling, not even my husband. Unbeknownst to me, God had already begun preparing me for His plan.

I can't believe I'm finally going to meet this little baby boy that's been growing inside me for nine months. I'm so excited to hold him when he comes out and see Steve hold his son for the first time. We sat and waited anxiously.

Both of our parents were arriving soon and we had the video camera ready so my mom could film part of the birth...from the head of my bed of course, no need for crotch shots.

Our family and friends started arriving, mingling in the room. Once my labor became more painful and intense, everyone left to go to the waiting room to anticipate the arrival of our baby boy.

After about five hours of labor-inducing medication, I had only dilated to one centimeter. Ten of course, was the goal. My pain from the contractions was severe now. It was as if a sword went straight through me from my lower back through to my stomach.

The anesthesiologist came in to give me my epidural. She had me lean over the side of the bed. "Okay, try not to move. I am going to insert a very long needle into your spine, and then after a few minutes you should feel relief."

I held onto the nurse who was standing in front of me. My inner dialogue argued. *Be still, she said. Kinda hard when it feels like my body is being twisted in half, but okay. I'll do the best I can.* So I did what she told me to do, through the pain, and remained hyper-focused on my breathing.

After yet another hour of agonizing contractions, it became unbearable. I kept repeating "this is not working... it's NOT working!"

"I'm going to go ahead and give you something to help you relax. It will not reduce your pain, but it might make you feel a little woozy," the nurse stated.

They kept giving me more drugs, simply putting me into a drug enforced stupor between the pains. Finally, I turned to Steve and

whispered, "I feel like I am going to stop breathing, I don't want any more drugs."

The nurse who had been paging the anesthesiologist was getting frustrated with her. My nurse knew how much pain I was in since the epidural wasn't working. Writhing in pain with these cyclic matters, I finally asked Steve, "Please! Dig your fist into my lower back, it hurts so bad!"

"Okay, like this? I know you are in a lot of pain, but I am scared I will make it worse," he replied. He was trying the best he could but was a little freaked out.

"Yes, just make a ball with your fist and push it into my back as hard as you can. You won't hurt me," I pleaded. "This IS NOT WORKING!" I finally exclaimed.

Steve, who was about to blow a gasket, turned to the nurse. Before he could speak, she interjected, "I'm calling the anesthesiologist back right now. This is ridiculous. She shouldn't still be in pain after the epidural."

The anesthesiologist finally returned and asked, "So, you're still feeling pain, huh?"

Self-control, Lisa. Don't yell at her idiotic question.

I kept my wits about me and responded politely. "Yes, I am still feeling all the pain. Also, all these drugs I'm getting, knock me out in between contractions are making me feel like I may stop breathing," I said.

"Ok, let me remove this epidural and insert another one," she replied.

She requested I sit up on the edge of the bed again as she pulled out the epidural. My contractions had reached a number 10 for pain level at this point. Yet, I had to sit still and not move while she re-inserted it into my spine. It was a lot harder to be still this time, but I had to do what I had to do. As soon as she replaced the epidural, they

laid me back down in bed. Voila! The agony exited my body with high velocity.

She had placed the needle into the wrong spacer in my spine the first time. I thanked God it didn't cause any damage to my spinal cord. I was still only dilated to a 1 at this point, but once my pain was under control, it only took about an hour for me to reach full dilation. Finally, I was ready to deliver this baby.

The hardest part was over, or so I thought. I pushed for almost two hours. *I don't understand why this baby won't come out. Is this a prediction for stubbornness?* I thought, jokingly. This baby boy was not having it. The doctor kept telling me the head was trying to come out, but retracting for some reason. They kept a good eye on monitoring the baby's heart rate and my blood pressure, determining whether to do a C-section.

"We'll give it a little longer with you pushing Lisa, but we may have to do a C-section," the doctor said.

"No, I don't want a C-section if I don't have to, I'll get this baby out."

At last, with a few more final pushes, I gave birth to my first 8lb, 4oz, 21in, long baby boy. He came out screaming at the world, which is always a good sign to hear the cry. I was happy to hear him cry. I think he was mad at me for making him come out of a warm and cozy place.

"6:05, you did it," Steve said. I fell back into the bed with relief. Time stood still. The room fell silent, all except for the baby boy who was still crying. He wasn't put onto my stomach like planned, and Steve wasn't offered to cut the cord as we requested. *Something's not right.*

I wasn't sure what it was, but I knew something wasn't good. I looked around at everyone's faces. No one was talking, or saying much of anything. There were only three words we heard: *it's a boy.*

“What’s wrong, is he okay?” I asked.

“I’m going to go ahead and cut the cord down here, then we’ll take him to the NICU and have some tests run,” the doctor mumbled through his mask. “He has some syndrome-like features, so we need to make sure he is okay.” Mic drop.

“Is he going to be okay? What do you mean, *syndrome-like* features? Does he have Down Syndrome?” I asked, all in one interrogative statement.

“Not necessarily Down Syndrome, but we’re unsure what’s going on. His head has an unusual bulge and his fingers and toes seem to be fused together,” the doctor explained. Second mic-drop.

The room seemed to be closing in on me, almost like I was in a dark tunnel. Confusion was taunting me. I wanted him to be okay. *Was this a nightmare? Was this really happening? Is he even going live?* My body shook as if I was standing in an arctic blast, yet I wasn’t cold.

“The shaking is a side effect from the epidural, and part may be from shock,” stated the nurse’s aide.

The nurse began pushing the button, calling for more help. “Hello?” Again. “Hello? We have a baby boy in room 308.”

Within a couple minutes, a rotund nurse undulated into the room and hovered over our baby when she asked, “Dad, can you come over here please?”

Steve walked over to see him while they checked his vitals. I looked over to the side dresser mirror so I could see his reaction since I was still lying flat while the doctor stitched me up. I hadn’t even seen my baby yet. *Maybe when Steve sees him everything will be okay. Maybe it’s not as serious as it seems.*

Steve broke down and sobbed, creating an image, etched in my brain forever. This was the first time I had ever actually seen him cry. My heart broke into a thousand pieces. I felt I had failed him.

Questions were swirling around in my head like a tornado: *What happened? Where did I go wrong? It wasn't supposed to be like this.*

I was supposed to hold him, cuddle him, nurse him and everyone would go home like a normal, happy little family. It shouldn't be doom and gloom when you give birth. Tears of joy, perhaps, but not like this. I couldn't wrap my brain around the situation. Throughout my entire pregnancy, I ate the healthiest I had ever eaten and taken superb care of my body. *Why did this happen to my baby? Why is he suffering? Is this punishment for stupid things I've done in my past?*

My mom, who was at the head of my bed filming, turned off the video camera. Her voice shaking and crackling said, "I'm going to give y'all some alone time." She kissed my forehead, laid the camera down, and walked out of the room.

The nurses in their muted scrubs hustled around then brought him over to the side of my bed. He was all swaddled like a burrito in a white hospital blanket.

"Do you have a name for him?" the rotund nurse who was holding him asked.

"Logan," I said.

She asked a second question, "What about a middle name for him?"

I stared at his sweet squishy little face. *He was adorable. I saw a glimpse of his bulged forehead, but he was the sweetest sight to me.*

The nurse asked her question for a second time, "Do you have a middle name picked out for him?" she repeated.

"Huh?" I muttered as I snapped out of my twilight zone.

"Um, Wade... Logan Wade," I responded.

"Okay Mom, give him a kiss. We need to take him to the NICU now and start running tests," she said bluntly. She lowered his head to me. I kissed his soft and squishy forehead and got my first whiff of

his scent. His sweet aroma made me want more of him. He was a precious sight and the most joyful scent I had ever smelled.

She scurried off to take my soft and squishy baby, who had *some kind of a syndrome*, to the NICU. I watched her as she scuttled off with the tiny being I carried for forty-one and a half weeks. The tiny being who kicked me while I would lie down and try to sleep. The being who made my stomach reverberate when he had the hiccups inside me. Panic slapped me in the face. My chest tightened. My brain finally began catching up, but catatonia hijacked my words, jailed them to the isolation of silence: *wait, please! Let me hold him first. Why can't I hold him? He needs to hear my voice. He needs to feel my touch. What if he thinks I abandoned him? Babies can sense their moms. What if he doesn't live and I never get to hold him?* But the words never left my mouth. I continued to question, *something*, somewhere along the way went awry, but *how?* My immediate knee jerk reaction was *guilt*.

The fact that this nurse asked me to say his name out loud forced me to focus on him, and not the nightmare I felt I was in. It was a small gesture, but a blessing nonetheless. This brief moment was validation that this tiny human was my baby, and this baby has a name. She could have easily rushed off to the NICU without batting an eyelash, especially since this was such a shock of unknown answers. Yet, she took a minute to normalize everything for me, bringing me back down to earth. I'm so thankful for her.

After my doctor finished up with my care, he walked over and sat on the edge of my bed and placed his hand over mine.

"I am so sorry," he said. My nurse walked up beside him with tears in her eyes, and they both were offering me condolences. "I'll be by tomorrow to check on you," the doctor finally said. He left the room.

"Would you like your family to come in now?" the nurse asked.

I looked at Steve. "Can we have a little bit of alone time first?" I asked.

"Sure, I'll go let your family know," she said.

Steve and I hugged for a long time, and then we cried.

"It's okay. It's not your fault... I love you," he whispered.

More nurses came in bringing medication and food. "Here is your pain medication. You should try to eat something too," one of them said.

"I'm really not hungry," I replied. I took my medication and was ready to see our family.

"You really should eat a little something to put on your stomach so the medication won't make you sick," the nurse urged.

I obliged and nibbled on a roll. "I can't eat anymore right now," I pleaded. My appetite was void.

"We need to go ahead and move you to your regular room, but the NICU physician will be coming in soon to talk to both of you first," she stated.

The NICU physician came into our room with a very large, thick medical textbook. She started speculating the situation in which she named off two syndromes.

The first was Crouzon Syndrome and the second was Apert Syndrome. "I would lean toward Apert Syndrome, due to the appearance of his hands and feet. However, we need to wait until Monday for the geneticist to examine him and give an official diagnosis," the NICU physician explained. This meant two whole days of waiting and wondering.

"I found a journal article stating most children diagnosed with either Crouzon or Apert Syndrome *might* have an average IQ. But, there is a good possibility he will have mental retardation," she continued.

I couldn't help but run through the grocery list of "do's and don'ts" during pregnancy. *Did I miss taking a prenatal vitamin? Was it the old house we had lived in when I found out I was pregnant? Perhaps there was lead in the pipes or paint. Was it because I was too stressed out during the school year teaching kids with behavioral needs? Were there pesticides on any produce I ate during my pregnancy? Maybe it's because I had to take antibiotics during my eighth month due to bronchitis. Who knows if these are valid concerns, but what I do know is I have to stop this irrational madness in my head right now.*

"So he is going to be okay right?" I asked with a glimmer of hope.

"Possibly. We're doing every test we can. Again, this syndrome is very involved so you need to understand there is a chance of mental retardation," she repeated.

Okay doc, I know this is your disclaimer, but come on, throw me a freakin' bone here. My glass needs to be half full and I need some positive vibes here, so give me some hope.

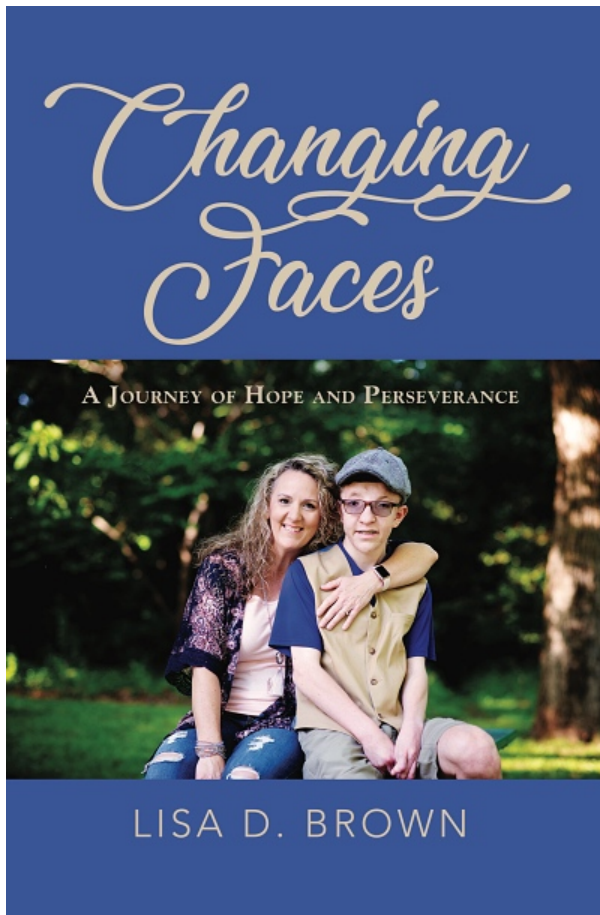
"Steve, you should go talk to everyone now, I'm sure they're all worried. They will be taking me to another room soon anyway." I said as we tried to pull ourselves together.

"Yeah, I know. I'll be right back," he replied.

About the Author

Lisa is a native Texan where she lives with her husband, two sons, three dogs, and ten chickens. She taught elementary special education for sixteen years, and now works part time in accounting. Lisa began blogging after her oldest son's multiple surgeries to share his progress with family and friends. She extended her writing focus to encourage and inspire other families raising children with disabilities. Besides writing, Lisa serves as a ladies' ministry leader and disciple maker in her church. She enjoys reading, traveling, gardening, crocheting, watching Friends reruns, and true crime documentaries.





Moments after giving birth to their first child, Lisa and Steve Brown are devastated to learn that even the doctors didn't know his prognosis, much less how to explain it to them. Their newborn son, Logan, looked profoundly different.

Changing Faces: A Journey of Hope and Perseverance
By Lisa D. Brown

Order the book from the publisher BookLocker.com

<https://www.booklocker.com/p/books/12362.html?s=pdf>

**or from your favorite neighborhood
or online bookstore.**