

The Joys & Possibilities of Life in a Special-Needs Family

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To my mom and her friends, who made the world a better place for their kids and for mine:

> Thresia Wood Jessica Baldridge Mary Sue Leu Michelle Presley Sharon Garrity

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## Introduction

Unexpected Circumstances, Unexpected Blessings

n November 16, 2010, our ship sailed into a tempest we had seen coming but hoped to avoid.

There had been signs. James didn't say as many words as most three-year-olds. We thought it was just because his big brother, David, never stopped talking. In an entire day, James said fewer than ten words, and not in sentences. Our good friend, an occupational therapist, pointed out that James didn't have motor skills expected for his age. He didn't play with toys appropriately. When he pushed a train along the track, he looked at the wheels, not the train itself. He didn't make eye contact, didn't respond when Daddy got home from work, and lost skills he had previously mastered (like forgetting the word *chartreuse*, which was his favorite color thanks to a *Blue's Clues* episode he watched over and over).

But it wasn't until we heard the psychologist say, "We believe your son has autism," that the full weight of the storm slammed into us, right there in a part-storage room, part-office space at our local elementary school. We sank deeper into the too-small chairs and looked at James as he tried to put a simple puzzle together with help from the occupational therapist assisting with the evaluation. He gave up quickly and tried to climb the shelves next to the window. A wave of thoughts hit me.

How different will things be now that James has a label, a diagnosis? How different will our family be? How will this affect our marriage? How will his big brother respond? What will their relationship be like? What will happen at church as he grows older but can't do what his peers can do? Everything seemed to change in that moment. They handed us a packet of information and gave us numbers to call for wait lists and more testing, then we took our son's hand—our autistic son's hand—and walked back out the doors of the school.

I accepted the inevitable and released my grip on the ship I had been sailing on for years. It was a ship of promise—I had promised God I would follow the rules and be a good girl, and I expected Him to promise me an easy life as a reward. I wanted sweet, smart boys, success in the ministry life we had devoted ourselves to, and no problems we couldn't solve with a quick library search or financial loan from my parents. These were the safety nets that had always caught me before.

My husband, Lee, refused to let go of his part of our battered ship. Built through his own hard work and determination, he thought anything could be accomplished with more effort. He would just add "Fix autism" to his to-do list and find a way to make it happen. His safety nets were his own efforts and resourcefulness.

Eventually, though, everything that had worked for us before failed, and we sank to the same spot.

Have you sunk too? Did you hear words from a teacher, a doctor, or a therapist that you keep repeating in your head—cerebral palsy, Down syndrome, cognitive delays, or even diagnosis unknown? Perhaps the piece of paper you received

from the doctor has words like *deformity*, *motor skill delay*, *language delay*, *emotional disorder*, *hearing impairment*, or *seizure disorder*. You can't get past these labels and descriptions. You can't see around them. The path you thought you were walking took such a sharp detour that you can't see where it leads or even where to put your foot for the next step. It can feel overwhelming.

My God, my God, why have you forsaken me? Why are you so far from saving me, from the words of my groaning? O my God, I cry by day, but you do not answer, and by night, but I find no rest.

Psalm 22:1-2

Save me, O God! For the waters have come up to my neck. . . . Let not the flood sweep over me, or the deep swallow me up, or the pit close its mouth over me.

Psalm 69:1, 15

Are you in the tempest now? Overcome? You may find yourself in the same spot we were in as we sunk to the bottom—shipless. But please know, there's reason to hope.

The floods have lifted up, O Lord, the floods have lifted up their voice; the floods lift up their roaring. Mightier than the thunders of many waters, mightier than the waves of the sea, the Lord on high is mighty!

Psalm 93:3-4

We went through fire and through water; yet you have brought us out to a place of abundance.

Psalm 66:12.

In the book of Acts, Paul was a prisoner on a ship heading to Rome when a tempest sent them way off course to the

island of Malta. The battered crew and passengers certainly didn't know what to expect as they struggled to shore. Were more difficulties ahead? Instead, we're told they were met with "unusual kindness." Throughout *Unexpected Blessings*, we'll follow the example of Paul as we navigate our own way through the storms we are experiencing. We'll meet biblical characters and real-life friends of mine who found themselves in Plan B situations. The suffering was deep, the nights were long, the cycles of grief seemed to never end, but they all found hope to help them survive and eventually found a new purpose so they could thrive.

Charles Spurgeon, the great nineteenth-century preacher, said, "What if others suffer shipwreck, yet none that sail with Jesus have ever been stranded yet." This was true for Job, Ruth, King David, Jonah, and Peter—they were never stranded. It's also true for me, my parents who have been caring for my sister with Down syndrome since her birth in 1977, and my friends Marie, Stephanie, and Greg. They took the same steps we are going to take in this book:

- evaluating the beliefs they held that weren't based on Scripture and therefore had to be replaced with true, biblical hope
- taking care of themselves through the storm
- getting to know a new group of people who could empathize
- making a positive difference in the place where they found themselves

I've been where you are today. Scared. Worried. Unsure what step to take next—unsure I could take the next step even if I knew what it was! But here we sit years later, my husband and I and other special-needs families, looking back on where

God has brought us. We accepted that not everything would go according to our own Plan A. We let go of what wasn't working for us anymore. We experienced the cycles of grief, and although they creep up occasionally, we have learned how to care for ourselves in tough times.

Lee and I met new people who understood our circumstances and could relate to our struggles. We even learned a new language—abbreviations like OT, PT, GF/CF, and ABA, plus all the insurance codes. But we no longer see our son's disability as something to fix, but as just part of who James is. We are still learning and growing, and I hope we never stop, but we are now to a point where we can give back to others on the same journey.

Soon after James's diagnosis, another mom with a son with autism encouraged me with this verse: "Those who sow in tears shall reap with shouts of joy!" (Psalm 126:5). Her son is my age, and she knew what we would face in the decades to come. That verse carries me through on the hardest days and makes the joyful days even more precious.

Our family has moved from a place of pain to having a purpose, and we can help you take that journey as well. The unexpected blessings you will experience will buoy you through the tough times, and with God's help, you will be able to look back with appreciation and joy.

## che

## Shipwreck

We must be willing to let go of the life we have planned, so as to have the life that is waiting for us.

E. M. Forster

In 2015, we packed up our lives and moved from rural Pennsylvania to suburban Texas. We left a church we loved serving for the previous eight years to start something new—planting a new church. Lee asked me how I felt about our new life, and I answered as I so often do when his big dreams change our plans, "Cautiously optimistic." It's kind of my motto. I'm not getting it tattooed anywhere soon, but I say it enough that Lee knows it will be my response to a fair share of questions. How do I feel about meeting James's new teacher? How do I feel about David auditioning for the next play? How do I feel about writing this book? How do I feel about going on a low carb diet for the month? *Cautiously optimistic*.

It's not that I'm a glass-half-empty kind of girl. It's just that I've been around the block enough times to know that things

usually don't go as planned. And that makes me cautious. But I've also been pleasantly surprised how every Plan B situation has worked out for my good and spiritual growth, so that makes me optimistic.

Our vision for the new church was to be welcoming to people with disabilities from day one. We see special-needs families as an unreached people group, since so many don't attend church. They feel isolated and lonely, and they need the hope the gospel provides and the community a church offers. According to the last census data, almost 20 percent of families in the United States include someone with a disability, ranging from autism to Alzheimer's.¹ That's one in five families. And that's way too many who may feel like they have to stay home on a Sunday morning.

Before Lee and I even started our church, we worshiped and served with a nearby congregation that was going to help us get our ministry going. We got involved in the community with other churches in the area. To meet special-needs families, we did outreach events, including sensory-friendly movies and free family photo sessions with a photographer who was also a special education teacher. We met over two hundred special-needs families in the area through these events. Many told us, "Let us know when your church is open! We'd love to come!"

At the end of our first year in Texas, it was time to start our church. But after all those months of sharing our vision, only two families committed to coming with us (and one of those families knew they would be moving out of state after just a few months). Two more families we met from the community joined with us, but both drove over thirty minutes to our weekly Bible study and both have teenagers with disabilities, so it wasn't always easy for them to get out.

Through the second year we met weekly in our home for Bible study. We hired a babysitter for the younger kids, and the older kids and teens usually ate together and then joined us for Bible study time. Most weeks it was nine adults, four kids under ten years old (three with special needs), and nine older kids (four with special needs). We loved being together, and the other parents knew they could relax because their kids would be safe because of the precautions we had made to our home.

But after two years of funding from our supporting church, the local association of churches, and our state denomination, it was time for them to evaluate their investment in our new church. We needed to be more self-sustaining, but the families who met with us weren't able to give the amount we needed to make the budget work. My husband worked two jobs in addition to church planting, and I worked three part-time jobs from home. Still, without help from our funding sources, we couldn't continue to devote time and our own resources to keep the church going. In July 2017, we officially closed as Journey Church.

It's hard to see your dream die. Especially a church you hoped would be a source of hope, love, and community to people who need it all so desperately (like my family). Our Plan A didn't work out, but God wasn't finished with us.

No matter what diagnosis you've gotten, it likely wasn't your Plan A. My parents heard "Down syndrome" in the delivery room after they held my sister for the first time in 1977. It could have come months before if they had chosen to do an amniocentesis to test for chromosomal abnormalities, but it still would have been a surprise. I suspected James had autism (or at least sensory processing disorder and language delay) before he was diagnosed with autism, but it wasn't Plan A. And even if you read every word of the file on a child you are adopting, there will be surprises once he gets home and adjusts to life with your family.

When we switch from looking at the big picture to everyday challenges, we realize very few days go as planned. One phone call from the school nurse makes me leave an online meeting and hop in the car. One missing ingredient can change the dinner plan, a big deal when your child has food allergies or food aversions. A few drops of rain can bring the party inside, causing a meltdown for your daughter who had her heart set on swinging.

If it's true for a day, it's certainly true for the year, and it's especially true for a lifetime. None of us are living our Plan A scenario.

For list makers, menu planners, and routine keepers like me, that can be bad news. My automatic response isn't, "Oh well. It's going to be a great day/year/life anyway!" It's usually, "Nothing is going according to plan! I can't function without the plan!"

Writer Paul Virilio observed, "The invention of the ship was also the invention of the shipwreck." We could say the invention of life was also the invention of a Plan B, at least from our human perspective. Adam and Eve thought their Plan A was to live in the garden of Eden forever. But sin entered through the choice they made, and so did their Plan B. But God came through with His Plan A—the redemption of the world through His Son Jesus Christ. He was fully God and fully man as He walked the earth two thousand years ago. He led a sinless life but took on the sins of the world, my sin and your sin. He alone could defeat death and restore our relationship with God, our creator. When we place our faith in Him and what He accomplished for us, we are adopted into God's family and become coheirs with Christ. The Holy Spirit abides in us and guides our thoughts, actions, and feelings. As sons and daughters of God, we can take each step He asks of us on this journey.

From Adam and Eve to now, each person has lived out his or her own Plan B. We see this throughout Scripture, including the accounts of Job, Ruth, Jonah, and Peter.

## Job-Steadfast Hope

One of the most drastic Plan B lives we see in the Bible is Job's. A righteous man, who like me probably believed he had earned an easy life since he was so good at following the rules, found himself sitting in a pile of rubble and dust, both figuratively and literally. He lost his children, his livestock, his servants, and his health. Yet, we're told he worshiped even after receiving so much devastating news (see Job 1:20). And after his wife told him to curse God and die, Job responded, "Shall we receive good from God, and shall we not receive evil?" (2:10).

The rest of the long book of Job records conversations between Job and his friends and Job and God. Job mourned the life he'd been given: "I will speak in the anguish of my spirit; I will complain in the bitterness of my soul. . . . I loathe my life; I would not live forever" (7:11, 16).

What did he want most of all? Someone to bridge the gap between himself and God: "There is no arbiter between us, who might lay his hand on us both" (9:33). He wanted to enter God's presence and hear from Him: "Oh, that I knew where I might find him, that I might come even to his seat!" (23:3). But even if Job had to live this life of suffering until he died, he still had hope. Hope that there was a purpose to his Plan B life: "I know that you can do all things, and that no purpose of yours can be thwarted" (42:2).

## Ruth-Follow God's Leading

Ruth experienced what we can assume was a good life early on. She lived in her homeland with her husband and had a close relationship with his family who had come to Moab from Bethlehem before the head of the family, Elimelech, passed away. After ten years of marriage, her husband and

her brother-in-law died, leaving Ruth with her mother-in-law Naomi and the widow of her brother-in-law, Orpah. This was certainly not Plan A for this young woman who didn't have any children of her own.

But she (being braver and more optimistic than I am) went all in on Plan B, moving back to Bethlehem with Naomi, "For where you go I will go, and where you lodge I will lodge. Your people shall be my people, and your God my God" (Ruth 1:16). How scared she must have been on that journey to an unknown place. Especially when Naomi encouraged her to turn back as Orpah decided to do. But Ruth had learned enough about the true God from her husband and his family to know that where His people were was a safe place for her as well. John Piper reflects on the life of Ruth, "When you think [God] is farthest from you, or has even turned against you, the truth is that as you cling to him, he is laying foundation stones of greater happiness in your life."

Ruth's story took some twists and turns once they were back in Naomi's homeland, but God guided Ruth's decisions, and she married Boaz and gave birth to Obed, who is the father of Jesse, the father of David, and in the lineage of Christ Himself. The people of Bethlehem, who had heard Naomi (which meant pleasant) change her name to Mara (meaning bitter), rejoiced with her, saying, "Your daughter-in-law who loves you, who is more to you than seven sons, has given birth to him" (4:15). As the Women's Evangelical Commentary points out, this is "an amazing statement in a culture in which sons were highly esteemed. This supreme compliment surely refers not only to Ruth's character (3:11) but also to her unusual commitment to care unselfishly for her aged, and even embittered, mother-in-law."4 Ruth felt safety and security even in her Plan B life, and so can you as you follow God's leading and rest in His presence.

## Jonah-God Knows Best

Jonah is one of my favorite Plan B stories because God gave him a clear Plan A and he came up with his own Plan B! God had to bring Jonah back to His purpose for him.

The book of Jonah gets right into the action with God saying to Jonah, "Arise, go to Nineveh, that great city, and call out against it, for their evil has come up before me" (Jonah 1:2), but Jonah went a different direction: "Jonah rose to flee to Tarshish from the presence of the Lord" (v. 3).

Jonah boarded a ship and, like us, encountered a storm. Even the ship's crewmen who did not know Jonah's God realized God was indeed real and trying to get Jonah's attention. "The men were exceedingly afraid and said to him, 'What is this that you have done!' For the men knew that he was fleeing from the presence of the Lord, because he had told them" (v. 10). God used the fierce storm to convince the crew to throw Jonah overboard as Jonah asked them to do, "So they picked up Jonah and hurled him into the sea, and the sea ceased from its raging. Then the men feared the Lord exceedingly, and they offered a sacrifice to the Lord and made vows" (vv. 15–16).

Most preschool age Sunday school classes can tell you what happened next—a great big fish swallowed Jonah, and he lived in the belly of the fish for three days and nights. Thankfully, you and I have never been in the belly of a fish. But we have felt lost, in the dark, and separated from the life we knew. You may even relate to Jonah's description: "For you cast me into the deep, into the heart of the seas, and the flood surrounded me; all your waves and your billows passed over me" (2:3). But Jonah knew this suffering served a purpose. That God had a plan for him.

Jonah prayed to God, and God answered his prayers by having the fish deposit Jonah onto the shore. Jonah fulfilled the

calling God had given him when we first met Jonah: "Jonah began to go into the city, going a day's journey. And he called out, 'Yet forty days, and Nineveh shall be overthrown!' And the people of Nineveh believed God. They called for a fast and put on sackcloth, from the greatest of them to the least of them" (3:4–5). After they repented, "God saw what they did, how they turned from their evil way, [and he] relented of the disaster that he had said he would do to them, and he did not do it" (3:10).

It would be a good story if it ended there, but it doesn't. Jonah was mad at God for having compassion on such sinful people. "Jonah went out of the city and sat to the east of the city and made a booth for himself there. He sat under it in the shade, till he should see what would become of the city" (4:5). God grew up a plant to shade Jonah but caused it to die the next day. When Jonah was sad about the loss of the plant, God reminded him the lives of the people of Nineveh were even more important than the plant. God's care for Nineveh is clear in this story, but so is His care for Jonah. God's love is big and wide, and also personal and specific. We see both on our Plan B journey.

#### Peter-It Starts with a Decision

Peter's Plan B story is a dream for all the dreamers. You're at work one day, doing what you always do, and then someone makes an offer you can't refuse. When Peter and his brother Andrew heard Jesus say, "Follow me, and I will make you fishers of men," Matthew writes, "Immediately they left their nets and followed him" (Matthew 4:19–20). One minute Plan A, the next minute Plan B. I'm sure Peter was excited, but he also had to be scared. Where would they sleep that night? What would they have for dinner? Peter strikes me as enough of an optimist to

assume it was all going to work out fine, even without a plan. They were familiar with the ministry of John the Baptist and had heard of this new teacher from Nazareth. Peter felt God's call on his life, and he followed in obedience.

It reminds me of the moment my parents got my sister's diagnosis of Down syndrome. There were no hints, no clues before she was born that anything would be different from all the other babies born two days after Christmas in 1977. But not only was she born with Down syndrome, she was also born with an intestinal blockage. Her body would not be able to process any nourishment. Syble was put on a helicopter to Oklahoma City for emergency surgery, and my parents got in an ambulance to follow as quickly as they could. This was certainly not Plan A for my mom and dad, who were just twenty-six at the time and having their first child.

At the hospital in Oklahoma City, a young doctor took my dad into a janitor's closet and said to him, "Look, your daughter has two issues. One will kill her. One will affect her life and yours forever. If you don't want us to fix the intestinal blockage and let her die, we would understand that choice." But like Peter, my dad was enough of an optimist to know it would all work out okay. And he knew my sister was part of God's purpose for his life. Other hard decisions would come (What therapies does she need? What can we do now to help her be independent in the future? When should we have more children? Will they also have Down syndrome?), but the first decision in that janitor's closet was an easy one.

Peter's first decision to leave the fishing boat and follow Jesus was an easy one too. A sharp turn from Plan A to Plan B. But that didn't make for an easy road. Peter certainly had highs and lows in the three years he walked with Christ, seeing Him perform miracles, forgive sins, command the weather, and even rise from the dead. Even when Peter betrayed his friend and

teacher, Jesus never gave up on him. He kept Peter moving forward to fulfill the purpose He had for his life.

## Everyone Lives a Plan B Life

When we receive a diagnosis, we can feel like the only ones who have ever been so devastated, so rocked to our core. But we see from the lives of Job, Ruth, Jonah, and Peter that no one is truly living their Plan A life. We all go through a shipwreck of sorts and have to survive the aftermath. You may feel alone and adrift, but God never takes His eyes off you. There's a short phrase in the middle of one of the best-known psalms that brings me comfort: "you are with me" (Psalm 23:4). He is with you.

Even more than you can imagine, He is grieved by the effects of sin we have to deal with on earth. It wasn't part of His original plan. A scene from *The Magician's Nephew* by C. S. Lewis illustrates this well:

"But please, please—won't you—can't you give me something that will cure Mother?"

Up till then he had been looking at the Lion's great feet and the huge claws on them; now, in his despair, he looked up at its face. What he saw surprised him as much as anything in his whole life. For the tawny face was bent down near his own and (wonder of wonders) great shining tears stood in the Lion's eyes. They were such big, bright tears compared with Digory's own that for a moment he felt as if the Lion must really be sorrier about his mother than he was himself.

"My son, my son," said Aslan. "I know. Grief is great."  $^5$ 

Once we accept that Plan B is the new Plan A, we can move forward to heal and discover God's new purpose for our lives. The process isn't easy, but it's worth it. When you accept your Plan B, you can be assured God will be there every step of the way with His peace, provision, presence, and power.

Even through all of his struggles, Job held on to the peace that surpasses all understanding: "For I know that my Redeemer lives, and at the last he will stand upon the earth" (Job 19:25). At the end of the book of Job, God provided him with a family and wealth again. But it was the peace of seeing God's faithfulness that he carried with him until his death: "And after this Job lived 140 years, and saw his sons, and his sons' sons, four generations. And Job died, an old man, and full of days" (42:16–17). Do you feel that peace? Some days you have to fight for it—you fall asleep praying God would surround you with His peace. But having a relationship with the Prince of Peace means His peace is yours, and you can learn to receive and rest in it.

God's provision for Ruth and Naomi was clear every step of their journey. Although they started out desperate and poor, when they arrived back in Bethlehem, God led Ruth to glean in Boaz's field. Boaz noticed her and asked his men to make sure Ruth got what she needed. After following the advice of Naomi, Boaz became Ruth's kinsman redeemer, a provision God had ordained generations before to protect vulnerable widows. Each time Ruth had a decision to make, God's provision was apparent. Have you seen it in your life? Maybe a friend shared an article that led you to find a solution for your family. Or a doctor knew exactly what test to order next. We find God's provision everywhere when we take time to look and give thanks.

God's presence was with Jonah on the ship, in the belly of the great fish, as he preached a message of repentance in Nineveh, and when he pouted on the hillside. His presence was clear when He provided a vine to shade Jonah and teach him a lesson about what Jonah should truly value. God showed His care for the great city of Nineveh and for Jonah as he sat alone. He

was omnipresent from ocean depths to hillsides. Do you think you've moved so far away from God that He may not be able to find you? That your confusion, anger, or bad decisions hide you from Him? That could never be true. His love is deep and wide and expands to reach you wherever you find yourself.

Peter had a front-row seat to see God's power on display through the life of His Son. He saw Jesus's power over nature when He walked on water, over demons as He cast them out of the people they tormented, over disease as He healed the woman subject to bleeding and many others, over death as He raised Lazarus, and over sin as He defeated it with His death and resurrection. Can you feel it when you are woken up yet again at three in the morning and you are still able to care for your child with love? Do you see it when your typical daughter defends her sister against teasing at school? And when you can look at a family member who hurt you with his words and actions and offer forgiveness, you know that is God's power working in and through you.

Are you ready to see more of God's peace, provision, presence, and power for yourself? It's all there—on your Plan B path.

## To Discuss or Journal

- 1. Do you consider yourself an optimist, pessimist, or realist? What experiences in your life led you to the personality type you tend to be?
- 2. Have you made a profession of faith in Christ? If so, share how that has made a difference in how you see your current circumstances. If not, think and pray about making that decision today. Talk to a friend or pastor about the steps to take next.

#### Shipwreck

- 3. How do you feel today about your life taking this Plan B turn?
- 4. Which Plan B story do you relate to most—Job, Ruth, Jonah, or Peter? What stands out to you about your similar journeys?
- 5. God's peace, provision, presence, and power are all available to you today. Which one do you need to be reminded of? Pray for God to display it in your life.