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*Freedom*

## CHAPTER ONE

# *The Storm*

Something was wrong. I sensed it moments after her birth. She barely cried in the delivery room and hardly thereafter. As the tension grew I began to probe each maternity nurse with the same question, “*Is she alright?*” I feared each response, but had to ask.

To my surprise, each response assured me our little girl was fine. My concern, however, refused to subside. Something wasn’t right; I could feel it in my gut.

Within 24 hours, my now standard question found its target as one nurse confessed, “*she’s a floppy baby.*” Surprised to hear anything other than the stock response that she was fine, I inquired into her meaning. “*She has poor muscle tone, which causes her arms and legs to fall to her side, unlike most infants who curl up in a ball when they cry*” she explained.

My suspicions were right. Something was wrong, even this nurse could see she was different.

Like the main character of a mystery novel, our little girl became more puzzling by the minute. She rarely cried, choked

with every feeding, and was unnervingly distant, by avoiding all eye contact.

In a single moment our lives were altered forever. Cloaked as a happy event, her birth detoured our lives into a series of life-long challenges we could never have anticipated. Life, as we knew it, would never be the same again.

God had a plan, one that was grand and far-reaching, but not our own. With great precision our daughter was chosen to be His method to bring us closer to Him. It would not be easy, however, it would be the most difficult task we had ever faced in our marriage together.

It's been nineteen years since our daughter, Dani, was born Autistic, deaf, and Failure to Thrive. Back then it felt as though life as we knew it was over. It seemed as though happiness had suddenly vanished, leaving behind nothing but a vicious series of trials. Like a runaway train, we were heading to a place we didn't want to go, but there was no way to stop it. We were heading toward disaster and all we could do was hold on tight and pray for God to sustain us.

Our years of raising a disabled child have been difficult to say the least, but through it all, the hope of God was always there, shining through. Like a delicate tulip pushing up through spring's cold hard snow, God's faithful love brought its warm light into our otherwise dark, depressing, and scary situation.

Our journey with disabilities, has uncovered many curious things not only about ourselves, but also about God. The most surprising thing I've learned about God is how intimacy with Him is often established in the midst of tragedy. In fact it seems to be His trademark.

Countless times, just as I was about to throw in the towel, He was there encouraging me to not give up. Reminding me that His plan, one custom-built just for me, is about to unfurl. It is ready and waiting, but I must persevere and never give up. I must believe, trust, and follow Him.

Through it all, I've come to learn that desperate times, painful as they are, are actually precious moments designed to cultivate greater intimacy with God. It is during the hardest of times He calls to us the loudest, hoping we will hear, respond, and come to Him.

If you are reading this book there is a good chance you're the parent of a disabled child. If so, my heart goes out to you. The pain of disability is intense and almost sure to drastically change the course of your life. It takes you where you never planned to go and often keeps you there longer than you'd like to stay. It is a challenge of a lifetime, and a lifetime of challenges.

But, God is always at your side calling you closer to Him. He will never leave you and seeks to guide you through your situation. He wants to carry your burdens and take all your pain

and heartache. He's been where you are and He understands what you are going through.

His first concern, however, is that you grow, not only that you will be comfortable. As we tend to focus on the here and now, He has His eye on our future and what we need to be strong, healthy, and firm in our walk with Him. With this in mind, our main objective should never be how to get out of the pain. Instead, it should be learning what He has to teach us through the situation He has strategically allowed into our lives. This new mindset makes all the difference in the world when seeking true freedom.

## SUBMERGED INTO THE UNKNOWN

What is your greatest fear? Without a doubt, mine is definitely water. I love it in small amounts, and I know I can't live without it, but large volumes scare me to death. A shallow clean pool is fine, but I never want to go into dark murky water. There are too many mysterious creatures that love to graze your leg, none of which can ever be identified. Everything from its depth, contents, and cleanliness is at question, making me want to steer clear no matter the cost.

Then there are large bodies of water; they are the worst. The mere thought of being submerged in a huge body of water, like a pea in an endless pot of stew, makes me wince with fright. I am

assured to know it was no mistake that I was born a 20<sup>th</sup> century Midwest Gentile. I'd have been a basket case trying to walk through the freshly parted Red Sea. Miracle or not, some dear soul would have had to carry me through, for I would have surely cupped my hands over my eyes and collapsed into a heap at the prospect of walking on land edged by walls of water on either side.

Beyond water, red or otherwise, anything unknown holds some degree of anxiety. It's a rare person who wants to go where no man has ever gone before. Feelings of uncertainty and hesitation are natural when met with the mysterious and unexplainable. More often than not we prefer to sit tight and enjoy a predictable calm. A little spice of life is fine, but only that which we can predict and control.

Unfortunately this isn't real life. Typically, the road of life is destined to dish out at least a few twists and turns that lead us to uncomfortable and unfamiliar territory.

Such is the road we walk as parents of special needs children. One moment things are fine, the next we find ourselves thrust into a world filled with great unknowns. *What is wrong with my child? What do I do next? How do I help my child? What lies ahead? How will we cope?* These are but a speck of the many questions we face once suddenly launched into this foreign and uncharted territory.

Entering into life with disabilities can be absolutely terrifying. Discovering your child is not as you had hoped brings a sinking feeling that can nearly drown your soul in grief. Great fear and trepidation can overtake you like a tidal wave, leaving you to wonder how you will ever cope in the future.

Moments of despair are unavoidable, waves of grief are inevitable, and feelings of resentment are nearly inescapable, but our ability to endure through these hard times hinges on one vital thing, that we keep our eyes on God and not ourselves.

Born the second of two children, Dani was our first little girl. Her brother Drew, three years older, was a healthy vibrant boy. He slept well, ate great, and played hard. All parents take pride in their children, but I was really proud of our son. I still am. He was exactly what I had always wanted in a child.

Like that special present on Christmas morning, his birth felt as though God had granted my fondest desire. Our experience with him made us anxious for another child, so we eagerly awaited the birth of our daughter.

My husband and I both wanted a girl. Long before she was ever conceived we prayed for her with great anticipation, then waited for the little one God would bring into our family. Without reason to believe otherwise, we trusted He would bless us equally the second time around, and He did, but not the way we expected.

God's plans stretched far beyond the blessing of another child. Far more than what we could ask or imagine, He sought to bless us deep within our hearts, in a way nothing else had ever done before. With our lives changed forever and futures heading for perpetual uncertainty, He had many great things awaiting us ahead, but first we had to be refined.

Once diagnosed with Autism and deafness, the little girl I had always dreamed of suddenly became everything I never wanted. Like an unexpected flood she came into my life, bringing with her the dark world of disabilities. I was confused, angry and discouraged and had no clue what to do with my emotions.

It seemed so unfair. Not only had I not asked for a child with disabilities, I quite frankly didn't want it. I couldn't imagine how God could ever consider her a gift, or why He would allow this into anyone's life. How could anything good come out of the situation? How could her and her disabilities be a gift from God? It was all far beyond what I could understand at the time.

My response to having a child with disabilities was a surprise to everyone, including myself. Friends and family naturally thought that I would be the one to readily accept our daughter's disabilities and assumed my husband would be the one to struggle most. I suppose, given my profession as a nurse, I would have assumed the same, but as it turned out nothing was further from the truth. When all was said and done, he accepted

her and her disabilities with flying colors, while I failed miserably.

On the outside I grieved as you would expect, but inside, a wicked battle was underway. It was as if her disabilities had flipped a switch inside me, bringing light to a very dark side of me, a side I'd never seen before.

Caught totally off guard, and with no prior exposure to disabled children, I was thunderstruck. As if pinned against the wall, with nowhere to turn, I instinctively went to God. I asked Him questions like, *“Don't you care about this child? Why did you allow this tragedy? Wouldn't a healing be the best thing for both her and us? Where were you when she was conceived and where are you now?”*

Like dark clouds growing more ominous each day, these unanswered questions loomed over our heads, but more so over mine. With claps like thunder they screamed the reality of her disabilities in my ear sending jolts of fear throughout my body. Our once happy and comfortable life was now over. I was beginning to see what our lives were becoming, and I was fearing the future like never before.

## THE FOG OF BITTERNESS

My fear of the future eventually began to take on a life of its own. Fed by grief and despair, it began to grow like a tiny

unsuspecting weed in the corner of my heart. What began as normal legitimate feelings of grief, were now becoming major stumbling blocks in my road to recovery. My sadness of having a disabled child was turning into anger, exhibiting itself as bitterness and resentment.

Why couldn't my daughter be normal? I couldn't figure it out. I would do anything to bring her to the point of healing, but there was nothing I could do. No medication, no therapy, nothing. I couldn't adjust the past, I couldn't change the present, and I couldn't alter the future. It was all completely out of my control and it was eating me up inside.

Stuck at this impasse, I grieved not for weeks or months, but I grieved for years on end. Unable to move on, unhappiness became the norm. My zest for life had been dampened for so long that despair had become a way of life. Dani would never be normal and I would never be happy. That's just the way it was going to be. The fight to survive was hard enough, fighting for happy required more strength than I had to offer, so I gave in.

What was once foreign had now become familiar. Having been suddenly submerged into the life-changing world of disabilities, I was becoming accustomed to the pain. They say misery loves company; it became my close, personal, and faithful friend. I repeatedly cried, felt isolated everywhere I went, or took inordinate amounts of time wallowing in self-pity. These were now my customary habits.

It wasn't uncommon for me to periodically throw a party, a pity party to be exact. They were easy to throw. I could have one any time I wanted. All I had to do was reflect on what my life once was and what it had become. In no time at all a fiesta was underway!

I've had pity parties anywhere. Restaurants, church, department stores, parks, playgrounds, schools, you name it and I've partied there. I don't mean to brag, but I was a master pity party planner.

But there's a problem with having these moments of self-indulgence. They lead us nowhere. Like heaping sandbags atop our shoulders they weigh us down and grind us to a halt, hindering our chance of healing and greatly displeasing God, who wants us to be free. Determining to abandon this chosen behavior is vital and one we must all choose to do. Failing to do so will inevitably lead us down a path we will not be able to alter later down the line.

It is never God's plan for us to surrender to grief. Move past it yes, but camp there no. That is why He took the time out of His busy schedule of running the world to pay me a visit, a visit that would alter the course of my life once and for all.

It just so happened to be during one of my standard self-centered celebrations. I had only invited me, myself, and I, but He came uninvited nonetheless. What's a person to do?

The merriment commemorating my misfortune was fully underway when His presence began to shift the mood. No longer the main attraction, my attention was now on Him.

What could He want? Why was He showing up now of all times? After all those unanswered prayers from the past why did He come now, uninvited? I wasn't sure I wanted to see Him at this particular moment, but He was already there so I sat back to hear what He had to say.

With ears perked, I was ready for a Word. He began by first pulling out something for me to see. It was a diagram, a map to be exact. A bit odd for a party I thought, but it caught my attention nonetheless. This was going to be interesting.

To my utter surprise, it was a map of my life. As if standing before an upright Plexiglas map at the mall, He pointed to a particular spot. Leaning in for a closer look, low and behold I discovered myself on the map, and I was standing at a fork in the road.

My eyes began to stare deeper into the illustration wondering what it all could mean. Softly and tenderly He began to speak to my heart. He said, *“Nancy, you have grieved long enough. Today you are at a fork in the road, and the path you choose today will determine the rest of your life. You can choose the path of bitterness, and grow to be a bitter old woman, or choose the path of happiness, and determine to be happy in the midst of*

*your trials. The path you choose today will be the path you will walk the rest of your life.”*

My pathetic party ground to a halt as His words of truth began to sink into my heart. He was right and I believed every word He said. Deep down I knew it was true, and it was a relief to hear. I had gotten stuck and it was time to move on.

My decision that day was not a hard one to make. I missed being happy and He knew it. The thought of becoming a bitter old woman didn't sound good in the least. It didn't fit my personality. Oh how I longed for the day I could be happy again. How I wanted the weight of grief to be lifted from my frame so I could walk without pain and discomfort. His words that day revealed to me two things; I had a choice and He had a way. Like a breath of fresh air my hope was renewed.

Did you know we were made to laugh and have fun? Along with children, laughter and joy are a gift from God (Galatians 5:22) so we should always strive to be happy. God wants us to have fun and live life to the fullest. When we smile, joke, play, and have fun, it makes Him happy. Our joy is His delight; therefore we should never feel as though our lot in life is to be desperate, alone, or in despair. As children of God, it is His greatest desire for us to be free, content, and strong in Him. We should never settle for anything less than that.

It wasn't hard for me to make my choice of which way to go the day God showed me the map of my life. His visit brought great clarity to where I was and where I needed to go. I was heading for disaster if I didn't choose that day, then and there, to be happy. My decision to accept our daughter as His gift to me determined whether or not I would find true happiness. The disabilities were not going to go away, but He had a plan. Now I was curious as to what it was!

In one moment I changed the course of my life, and I am so glad I did. Bitterness had taken root in my heart and I hadn't a clue. I thought I was doing all the normal things a woman would do in my situation, and I was, but it was time to move on.

Once exposed for what it was, I wanted the bitterness gone. Like a broken rotten egg, suddenly I couldn't get rid of it quick enough. I wanted as far away from it as possible. My grief had become toxic and it was time to move on. I chose that day to be happy, and it was the best choice I have ever made for my family and myself.

It won't surprise you to hear that choosing to be happy has not spared us from further trials. We continue to experience our fair share, but God is always with us.

I continue to experience times of frustration when pushed to my limit, and the enemy is always there to tempt me to throw another pity party. But I always remember that day when God

paid me a visit. I can still feel the couch give as the weight of His glory settled at my side and how honored I felt that He would take the time to show me the map of my life.

How merciful it was of God to warn me where I was heading. What a blessing it is to have been spared a life filled with bitterness and resentment. Seeing my true condition enabled me to change my course, so that I could begin to follow Him. Is He calling you to do the same?

What do you do when you don't get what you want? Have you taken the time to look at the map of your life? What road are you on and where is it leading you? Perhaps you are at your fork in the road and it's time to make a choice. Perhaps this is why God has you reading this book.

Maybe God is signaling a warning. Could it be you are on the road of bitterness? Might you be harboring deep seated anger? Are you stuck in a cycle of grief and cannot get out? If so, change your course now.

The longer you wait, the harder it will be to turn back. Given the warning I received, I believe there are points of no return in all our lives. Why risk going too far? Determine to be happy and choose to move on.

Paths of bitterness, resentment, anger, blame, and self-pity, only lead to a dead end, which is exactly where Satan wants you to go. He wants you frustrated, tired and without hope. In

becoming so, we are rendered useless for God, and all joy, happiness, and freedom that is truly ours, is stolen.

Our key is to trust God! Only He can guide you onto roads paved with peace, contentment, and faith. He has a specific purpose and plan for you, which involves the very circumstance He has allowed into your life. In Him, nothing is impossible or beyond His reach. He can take any situation and use it for His good.

Is your heart hurting today? Maybe you've hurt for so long your heart is numb from the scars. Perhaps you've accepted that your life is what it is, but you aren't happy about it one bit. You cope but you have no hope. You're alive but feel as though you have no life. The storms of disability have shattered your heart, your life, your family, marriage and perhaps even your faith.

Dear one, take it from a veteran: left unchecked, these negative feelings will eventually drain every ounce of life out of even the cheeriest of hearts. You are no exception.

Wherever you are in life, it isn't too late to turn around. God is ready to show you where you are and show you where you need to go. All you need is an honest heart that is willing to change its course. Will you do that? Will you walk the journey ahead to find the Promised Land God has waiting for you?

Oh, how I pray that you will go where God is leading you. Don't be afraid to leave the familiar behind. God's plans will

always exceed any of our own. They will never harm us or bring regret. They are perfect and just for you!

Look at the map He has set before you, listen to His voice, and follow Him. It is then you will begin to find the true freedom that awaits you.