

HELP!

MY GRANDCHILD
HAS A DISABILITY

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INTRODUCTION: ONE FAMILY'S STORY

We were looking for a little peace and stability. I had finished school, gotten married, and taken my first teaching job. We had moved from the East Coast to the West Coast, had our first child, and were preparing for our second. We were also in the process of buying our first home. With changes coming at us at what felt like the speed of light, we yearned for a taste of the quiet life.

No one could have prepared us for what came next.

Early one evening, we drove to the hospital. My wife was in labor with our second child. The nurses welcomed us at the door and seated her in a wheelchair. We joked nervously about a “throne on wheels” fit for a queen. Having turned down the amniocentesis test, due to its risks, we prayerfully anticipated a healthy delivery.

The nurses at Henry-Mayo Newhall Hospital in Santa Clarita, California, were outstanding. They were witty, alert, and light-hearted. Their joking soothed our nerves. The doctor, on the other hand, was all business, as we'd hoped he would be. With the stage set for a perfectly normal birth at an excellent hospital, all was well . . . or so we thought.

When the moment of delivery arrived, I was ready to give our little girl the trendy Laboya bath. This was supposed to soothe the newborn, as it put her back in a state of liquid suspension, simulating a mother's womb. The already focused physician was hypervigilant. Why couldn't he just lighten up a little? Aren't births supposed to be happy occasions? This doctor was stealing our joy! After all, all was well.

But all was not well.

As our sweetheart entered the world, she hardly made a sound. The silence, combined with the looks of panic our doctor gave the nurses, sent a sick feeling to my stomach. Our little girl was in trouble. I was in trouble. What was usually a noisy, happy moment when the pink, squalling little bundle bursts forth making first sounds was a deafening hush. The doctor continued to struggle as he again exchanged glances with the nurses.

Although the delivery team reluctantly allowed

me to do the Laboya bath, I held our baby loosely. She was limp, motionless, and blue. Finally, the team whisked her off to the nursery, or so I thought. No! It was off to the Neonatal Intensive Care Unit (NICU). While they struggled to be polite and sensitive to our feelings, their facial expressions and overall quiet showed clearly that something was wrong. I was getting sicker and sicker in my stomach as my wife rested, unaware that anything was wrong.

That night, I drove home praying, numb and scared. Although I still had no idea what was wrong, I knew for certain we were bracing ourselves for something bad. Exhausted, I dropped off to sleep still nauseated. I no sooner got to sleep when the phone rang. It was my wife. She was crying. "They won't let me see our baby." In a sleep stupor, I recklessly drove several blocks to the hospital and parked in the wrong lot. As I ran through the front door we had entered joyfully just hours earlier, one of the nurses who helped deliver our baby met me. She stammered on the verge of tears, "I need to talk to you about what's going on."

I froze. "We had to take your daughter to the NICU because her heart stopped. We were able to revive her, but she's doing very poorly." Then she

said the words I couldn't bear to hear: "She may not live."

I raced to see my little girl. There were so many wires and tubes attached to her that I could hardly find her. I looked up to see the nurse watching my reaction. She covered her mouth and ran for the door, crying. My legs felt like they would buckle. "Lord, not this, please" repeatedly crossed my mind.

Making very little eye contact the doctor repeated the nurse's message, but with much less empathy. "Things are bad. Her heart stopped and we spent twenty minutes resuscitating her. She may not live. If she does live, she may have additional brain damage." The word *additional* hit me like a freight train. It was final. The only thing we knew for certain was that our little girl had some sort of brain damage. That point was certain. The doctor also told us that if we wanted to confirm the diagnosis we would need to do a chromosome test. I had no idea what he was talking about.

After two weeks of waiting, the first chromosome test was thrown out due to accidental contamination. When we were asked if we wanted to do another test, I impatiently responded, "No, you're not putting my little girl through that again." So we moved forward with no clear

genetic testing, only a cluster of symptoms that characterized Down syndrome. Our hearts ached.

Down syndrome. I hated those words. What I hated worse was *Down's baby*, or just *Down's*. I wanted *up*.

Our pediatrician called several weeks later and said in broken English, "Your baby is trisomy 21." Thinking there must be language confusion, I asked impatiently, "What did you say?" She responded, "Your baby is trisomy 21, sir, Down syndrome." The mind-numbing last two words required no explanation. Several of my family members involved in special education often referred to kids in their classes as having Down syndrome. In the vernacular of a former generation, I was the father of a retarded child, or as some would say, a "Mongoloid baby." That cut deep. What responsible human being would come up with such a title? What sensitive society would use it?

Several thousand miles away from family, alone and crushed, we tried to move forward with life. At church, people genuinely tried to encourage us. One woman asked sympathetically, "Do you plan to keep her?" My first thought was, "Well, what else would I do with her?" Someone explained later that the previous generation was encouraged

to institutionalize children “like this.” “Like what?” I fired back. I had entered the world of language hypersensitivity. I was taking a nose dive.

My mind kept wandering to verses like:

Children are a heritage from the LORD.

(Psalm 127:3)

All children? Maybe not some children. And then there was another verse:

Take delight in the LORD,

*and he will give you the desires of your
heart.*

(Psalm 37:4)

What I desired was a normal, healthy baby. These verses were not working for me. The confusion was overwhelming. In a particularly dark moment, life seemed like it was over.

But life was not over. A bright new day had dawned for my entire family, although it would take a while for us to realize it. God’s gift of acceptance would ease the pain and keep us going. But that would take some time and personal growth.

Today my daughter Joanna is thirty years old, healthy and quite happy. As a family, our lives are

rich with God's grace. Daily, we experience great contentment. My other three kids (who have compassion ahead of their years) dote over their sister and enrich her life. God *has* given us the desires of our hearts: children, all children, are a gift from the Lord. His mercy lifts parents and grandparents up and carries them over every rough road. And his light breaks through the darkness.

I share my family's story because I believe that our experience is not unusual for families into which God places a child with a disability. What might be unusual, however, is the role grandparents and surrogate grandparents have played, and continue to play, in the life of my daughter and the rest of my family. So what is the role of Christian grandparents in the life of a grandchild with a disability? That's what this mini-book is about.

What Is a Biblical Grandparent?

The day your first grandchild was born you were not invited to consider grandparenting; suddenly you *were* a grandparent. That's because grandparenting is a calling. Callings are not freely chosen. In the truest sense, callings are imposed on us. They are not sought, found, or discovered; they are answered.¹ At first, this arrangement may not sound inviting. In fact, you may feel trapped. But just as God gives us our mission in life, so he also resources and trains us to do the work well. He can even give us an unexpected desire to love and care for a child that emboldens our hearts. But calling has another characteristic which may surprise us: we will never retire from our calling. In his book *The Call*, Os Guinness writes,

*God calls men and women who will be committed to their life tasks with no reservations, no retreats, no regrets.*²

This is true for all Christians, but is especially important to remember when disability enters our families. More on this later.

The needs of grandchildren and their parents help define the grandparent's role. Grandchildren are royal blessings. Proverbs 17:6 tells us,

Children's children are a crown to the aged.

But what if your crown is not what you expected? What if your grandchild has a disability? This mini-book offers grandparents their honored place as kings and queens in their families. If the Lord has blessed you with a grandchild who has a disability, then roll up your sleeves and get ready to polish that precious and beautiful crown!

Parenting a child with a disability can be a blessing. Grandparenting a child with a disability can be a delight! As the parent of a thirty-year-old young lady who is blessed by two sets of godly grandparents, I have discovered that grandparents can make a crucial difference. Let me explain what I have learned from Scripture and from how my daughter's grandparents illustrate its principles.

Accepting Your Role

In many ways, grandparenting a child who has a disability is like grandparenting a child who does not. But there are unique blessings and challenges which come with grandparenting (and parenting) kids with disabilities. I'm primarily writing to grandparents, but I want parents to hear this conversation as well, because interchange between these two family roles is important. In short, grandparents must *respect* the role of parents, while parents must *accept* the role of grandparents.

In order to understand family relational roles in the Bible, we must first understand the biblical home. In the Old Testament the home was called "the house of the father." The father's house was made up of what we refer to today as the *nuclear family* as well as extended family, including aunts, uncles, and cousins. This is important to grasp, since Jesus describes heaven this way:

My Father's house has many rooms.

(John 14:2)

In Bible times, when a young couple married, the family would often build an additional room

on the father's house for them. Yes, they were one big, happy family! Because the grandparents were the oldest surviving family members in the home, they played a critical role. Scripture was the fountainhead of all learning and the grandparents were the living examples. The example of deceased relatives also played a significant role as it lived on through the stories grandparents told the family. Deceased ancestors lived and spoke through the stories of grandparents. Life in the house of the father was very good!

Psalm 128 compares a blessed home to an olive tree with little shoots springing up and surrounding it. The imagery speaks vividly to the gift of children in the home. But the psalmist goes on to describe a fruitful home as one in which parents see their children's children (verse 6). And seeing involves much more than domestic bliss. On the one hand, living to see your grandchildren is an indescribable blessing; on the other, it is a call to fulfill grandparental duties which will entail hardship. No wonder Martin Luther called Psalm 128 a psalm of comfort for those who experience challenges in the home.³ The psalm also reminds us that not all people will be able to have children. Those of us who do will be blessed all the more to see our grandchildren be born and grow up to maturity.