

And He Will
Lift You Up

And He Will Lift You Up

A Message of Hope in
Disability, Depression, or Fear

Zanina Jacinto



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In Loving Memory of my Dad

José M. Jacinto

I love you, Daddy. Thank you for loving me, teaching me,
protecting me, and encouraging me.

I miss you very much.

It is only when we get hungry spiritually
that we receive the Holy Spirit...
He imparts to us the quickening life of Jesus,
making us truly alive.
He takes that which was “beyond” us and places it “within” us.
And immediately, once the “beyond” has come “within,”
it rises up to “the above,”
and we are lifted into the kingdom where Jesus lives and reigns
(see John 3:5).
—Oswald Chambers

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Foreword



I REMEMBER BEING a new mom and trying to physically juggle a grocery cart, my infant son, and my purse, quietly praying, “Lord, I need another arm!” My rheumatoid arthritis was disintegrating my shoulders and I was in a great deal of pain. A man approached me to offer assistance and I jokingly said, “New moms should be given an extra arm!” He responded by saying, “Yes, and I have just one.” I looked up at him and saw his shirt-sleeve pinned up at the shoulder. I had prayed for an extra arm and God answered my prayer—specifically. I knew then I was not alone in my journey of illness mixed with motherhood.

Zanina has experienced her own journey that both humbled and encouraged me as I read *And He Will Lift You Up*. I may worry about finances, health insurance, or even the loss of someone I love. She has experienced them all and more and yet has continued to look to the Lord with expectation of what He is going to do next.

Often the pathways of life seem confusing. Why would God watch Zanina surrender to His will, completely depending upon Him—as a single mom parenting a child with a disability—and then allow her to have a debilitating chronic illness of her own?

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Why would He guide her back to college and establish her in a career where she changed lives for the better, only to see her resign from her teaching position a few years later, MS having robbed her of strength and ability?

There are no easy answers. But Zanina shows us the One who holds the answers. She worships the Lord even when He doesn't provide explanations, even when there appears to be no logic.

John Piper writes in his book, *The Hidden Smile of God*, "Irony and disproportion are all God's ways. He keeps us off balance with His unpredictable connections. We think we know how to do something big and God makes it small. We think that all we have is weak and small and God makes it big."¹ These words have come to life in Zanina's testimony. Danielle's cerebral palsy and Zanina's multiple sclerosis led to a book, the one you now hold, that inspires and strengthens people in their deepest need. Zanina didn't point out her big plans for the Lord and demand Him to bless them. She simply followed where He guided her day-by-day.

Getting notes on paper, much less writing a book, is a challenge for one who deals with cognitive difficulties that are present in neurological conditions such as multiple sclerosis. That Zanina lived this is courageous. That she got her experience down on paper is admirable because it is even more of a struggle than for a healthy person.

When I began Rest Ministries in 1997, a Christian ministry for the chronically ill, I knew that there were many people who lived quietly with chronic illness. Oftentimes their symptoms, like severe fatigue or numbness in their limbs, are invisible to healthy people. I hoped to bring these people together to encourage them and bring them alongside one another in their seasons of illness—regardless of which side of heaven they experienced physical healing.

Foreword

Zanina's vulnerability and faithfulness to her Father is the kind of message I will share with others. Her writing has a voice of gentleness and grace. It's as though all the Scriptures she shares are given to you over a cup of hot tea and with a warm, tender squeeze on your arm that assures you it will all be okay.

Life with a chronic illness is never easy; nor is parenting, especially when you are a single parent or have a child with a disability. But regardless of where you are on your own journey, *And He Will Lift You Up* is sure to calm your spirit and give you faith to hang in there another day because Zanina's enthusiasm for the Lord will assure you that God is faithful.

My comfort in my suffering is this: [God's]
promise preserves my life.

—Psalm 119:50

—**Lisa Copen**

Founder, Rest Ministries
www.restministries.org

Acknowledgments



To God, and God alone, be the glory.

“**W**E GIVE CREDIT to human wisdom when we should give credit to the divine guidance of God being exhibited through childlike people who were ‘foolish’ enough to trust God’s wisdom and His supernatural equipment.”

—Oswald Chambers

Thank You, Lord, for every word that is written on these pages, for every moment of life these pages reflect, and for every life this book will touch. God bless each one. Amen.

A Call to Strengthen One Another



A CALL TO strengthen one another? How can I strengthen someone else when I have no strength for myself? I've asked myself that question too many times. And I venture to guess that you have, too. Sometimes I just feel so weary. My circumstances don't *seem* too difficult, they *are* too difficult. I look back and I don't know how I made it through the pain. And yet, somehow I do know. It's a faith that to some seems silly. A God that many care not to acknowledge.

Is my faith impractical? Some may think so. But is it real? Absolutely. As real as the disease that robs my body. As real as the tragedy that gripped your heart and stole your breath. Adversity distorts itself in many guises. It always strikes at an unknown hour. And no one is exempt.

An impractical faith? In the world of logic, perhaps. In the hearts of those who know and love Christ, unequivocally, no. It is something I don't claim to understand, but as I wrote this book, I came to know and desire it all the more. Faith in my Savior has sustained and proclaimed my life as beautiful, purposeful, and greatly loved. May the pages you now hold bring you hope, healing, and the gift of an extraordinary faith of your own.

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I Have Prayed for You

And the Lord said:
“Satan has tried his best to separate all of you from me,
like chaff from wheat.
But I have prayed for you, that your faith should not fail;
and when you have returned to [Me],
strengthen your brethren.”

—Luke 22:31, MSG; verse 32, NKJV

This morning, while making breakfast, I looked up on my windowsill and saw this Scripture. They are Jesus’ words to Simon Peter. But they are also Jesus’ words to you and me: “I have prayed for you.” Knowing this makes me feel wonderfully safe and loved.

The first time God ever showed this to me, I was reading the book of Romans during a very painful and trying time in my life. I read, “Christ Jesus...is at the right hand of God and is also interceding for us” (8:34). *Wow!* I marveled. *Jesus is actually interceding for me!* I couldn’t believe it. Jesus actually prays for *me*. Now that’s intense. That’s the power and love of Christ for us. That’s knowing that when I’m under attack with fear, depression, doubt, temptation; when my body is broken and my spirit is weak...Jesus is praying for me...and He’s praying for you.

Strengthen Your Brethren

For God’s gifts and his call are irrevocable.
—Romans 11:29

The Lord has a purpose for each of our lives. Disability doesn’t change that. Tragedy doesn’t erase His plans for us. He created us with special and unique gifts and talents. We can use them for Him, or we can use them for the enemy. Jesus said, “He who

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is not with me is against me” (Matthew 12:30a). That sounds pretty harsh, but it’s also truth. God always tells it to us straight. He’s honest about the good and the bad. He gives us free will and the Truth of His Word so we can make informed decisions. If we don’t like what He says, or if we think we are not able or worthy to do what He says, we only deceive ourselves. God works through *willing* vessels, not perfect ones. He loves us. And whenever we turn away from Him (in little or big ways), whenever we choose to give up, whenever we let circumstances steal our faith, God grieves. But He is always calling us back to Him, praying for us, forgiving us as we repent, strengthening us to move on with Him, and calling us to strengthen one another.

A Call to Motherhood



Danielle

THROUGH MY DAUGHTER, Danielle, God opened my eyes and changed my heart. A few months after Danielle was born, my sister, Michele, handed me a piece of paper. It was a column that Erma Bombeck had written about the mother of a disabled child. It has circulated the Internet under several different titles, one being “The Special Mother.”¹ Erma captures the heartbreak and blessing of parenting a child with a disability. She writes:

She will never take for granted a spoken word. She will never consider a step ordinary. When her child says ‘Momma’ for the first time, she will be witness to a miracle and know it. When she describes a tree or a sunset to her blind child, she will see it as few people ever see [God’s] creations.²

I cried when I read Erma’s column. But today I smile. My daughter blesses my life in numerous and wonderful ways. Danielle was born with cerebral palsy (CP) and a love for life. She fought hard to take her first breath, to master her first step, and

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to make her first friend. Erma was right. I have never considered a step as ordinary. Each one has been a greatly treasured miracle. And though Danielle and I have lived with ignorance, cruelty, and prejudice, God faithfully stands beside us and lifts us up beyond these injustices. He enriches my life through the gift of this child. And through her, I see Him more magnificently.

Danielle is now twenty-six years old and holds a bachelor of science in special education. She is a beautiful young woman with wisdom born of pain and triumph. Danielle's first trauma began before she was even born. It was April 18, 1985. I was six months pregnant. Driving home from a Bible study at the house of my friends, Brent and Ginny, I was seized by horrible abdominal pains. They weren't contractions. This pain was constant and unwavering. I began to vomit again and again until my stomach felt as if it were squeezing through my esophagus. I was staying with my friend, Patti, who wanted to take me to the hospital. But I thought it was just a bad case of the flu and wanted to stay home. By morning, Patti found me curled up in a fetal position, barely able to move and still in excruciating pain. She took me to her obstetrician. The receptionist, aghast the moment she saw me, rushed me into an examining room.

"She's dehydrated," the doctor said without hesitation. "Patti, you need to take her to the hospital."

The Community Hospital was closest. Once there, an entourage of doctors arrived and a multitude of tests ensued. My stay was brief. I was quickly transferred to a hospital with a neonatal unit.

I was scared. I was still in pain. *What was my baby feeling?*

My husband was in Rochester, New York, on a per diem job. My parents were on Long Island. I was in New Jersey. But I didn't have much time to think about that. All I cared about was my baby. I had never been a mom before, but my latent mommy-gear kicked in fiercely. I asked about every procedure

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and every medication. I even had the emergency room doctors call my doctor in New York. I didn't take my eyes off the fetal monitor. I prayed and prayed. I cried and prayed some more.

Twenty-four hours later, the pain was still unrelenting. Then contractions began. Doctors gave me medication to stop preterm labor. For sure, the baby had had enough and just wanted *out!* But we had to keep her *in* as long as we could. In the morning, the obstetricians consulted a general surgeon.

"We'll have to take X-rays of your abdomen," the surgeon informed me.

Oh no! That can't be. You don't do that when you're pregnant! My mind stumbled for understanding. "But Doctor, won't the X-rays harm the baby?"

"It's imperative that we have a better view of what's going on. At this point, the X-rays are critical to your health and the health of your baby." I conceded...and prayed some more.

The X-rays revealed a bowel obstruction. I was scheduled for surgery to remove it on Sunday morning.

"Wait! Wait! What about the baby? You didn't say anything about the baby! Are you taking her by cesarean section?"

"No, we won't be cutting into the uterine wall. We'll perform the surgery around her," replied the surgeon in an attempt to reassure me. But I didn't understand how my unborn child would be safe while I was under anesthesia.

"Couldn't that amount of anesthesia kill her? She's so small."

"The anesthesiologist will take care of you both."

I wasn't sure how that would work, but Danielle is here to say it does! (I recently learned that with certain substances, like general anesthesia, the placenta helps to regulate the amount that reaches the baby. God takes care of everything!)

After the surgery, I felt great, even though I had a vertical row of staples down my abdomen, a Nasogastric (NG) tube down my nose, an IV in each arm, a catheter, and deep injections of

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steroids every few hours to promote the baby's lung development. I was healing well, labor had stopped, and I was happy.

On Tuesday afternoon, after they removed my catheter, I felt a warm trickle of fluid. I buzzed the nurse. With embarrassment, I told her, "I'm sorry. They just removed the catheter and I think I may have had an accident."

"Don't worry," she said with a chuckle. "It happens a lot."

She came to the room and drew back the sheets. Her face went white. Frantically, she hit the emergency button, yelling, "STAT! STAT! Labor and Delivery!"

I had hemorrhaged. My bed was covered in blood. Contractions began again and did not stop until Danielle was born at 4:44 a.m. on Thursday morning, April 25th—she wasn't due until July 2nd!

God had placed her in my heart and in my hands.

And every day I place us back in His.

A Search for Answers

Danielle was born ten weeks premature with a birth weight of 3 pounds 5 ounces (dropping to 2 pounds 13 ounces in the first few days). She spent two months in the hospital, her little body struggling to survive. Doctors and nurses worked round-the-clock while friends and family prayed without ceasing. Upon release from the hospital, her weight just under 5 pounds, I was instructed to watch Danielle closely for any unusual stiffness or limpness.

"Danielle is stable, but we cannot, at this time, determine her prognosis," reported her doctor. "She may be perfectly normal. She may have motor problems. She may have learning disabilities. We will have to wait and see."

"What would it mean if Danielle were stiff or limp?" I asked. They would not say.

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I clutched my daughter close to me, grateful that God had seen her through—had seen us through—the traumatic whirlwind of those two months; thankful to be taking her home where I could care for her and hold her as my heart had been aching to do for so long. In those few months, I learned how very fragile life is. I also learned how God gives strength and wisdom in abundance to those who call upon His name.

A parent's job is probably the most important and difficult job in the world. Our trials began early as I quickly noticed how stiff and rigid Danielle's body was. It was difficult to hold her, to feed her, to change her. She never snuggled close to me or relaxed in my arms. I continually relayed my concerns to the pediatrician, who repeatedly attempted to pacify me, "Just give Danielle's growth more time."

Not only was Danielle stiff and rigid, but time revealed marked delays in her physical development. In spite of the pediatrician, I endeavored to have Danielle seen by a neurologist, only to have my efforts squashed by the firm rejection of his receptionist. "I'm sorry. You will need a referral before I can schedule an appointment." But our pediatrician would not give us a referral. I wish I had found a way to have a specialist examine Danielle immediately, but I was a young mother with little medical knowledge or political savvy—at the mercy of the "medical experts."

It was not until Danielle was seven months old that our pediatrician referred us to a neurologist. We waited an unbearable six weeks for a new-patient appointment. Several days after the examination, the neurologist called.

"Danielle is a bright and alert infant with slight motor delays. Here is the phone number for United Cerebral Palsy (UCP). They have an excellent Infant Stimulation Program. Give them a call to schedule an evaluation for your daughter."

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“Why am I calling UCP? What’s wrong with my baby? Why isn’t she rolling over yet? Why is she so stiff? Please tell me what’s wrong.”

The doctor refused to give me a diagnosis.

“Who referred you to me?” he inquired. “If you call your pediatrician, she will give you a diagnosis upon receipt of my report.”

I frantically called the pediatrician.

“I’m sorry, but I am not able to give you a diagnosis since I am not the physician who performed the neurological exam. I’m sorry that he referred you to me, but you will have to call him for the details of the report.”

I was fuming with rage. *How could they do this to me? Did they have to play these political games with me? Just tell me what’s wrong!*

I look back now and realize that I was begging these doctors to “label” my child. I wanted a name to place with my fears. No matter what they said (or didn’t say) to me, I knew there was something wrong. Most parents do. Like myself, they desperately search for a diagnosis, because with it, hopefully, answers and help will come.

I called the neurologist again, desperate and outraged, and demanded a diagnosis.

“I suspect your child has cerebral palsy.”

All the anger and fear that had built up within me over those last few months broke in a torrent of tears and pain.

Well, now I had a name to call the monster that plagued us.

But I had no idea what cerebral palsy was—was this what Jerry Lewis did his telethon for?—or what it would mean to us.

I learned of Danielle’s diagnosis the night before the annual cerebral palsy telethon, hosted by Dennis James—not Jerry Lewis. I was a mother consumed; and so, I sat for almost forty-eight hours in front of the television watching beautiful children share their struggles and triumphs. Their smiles and precious laughter were more remarkable than anything I had ever seen.

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There were children in wheelchairs and children in leg braces. A little girl sang beautifully and proudly, supporting herself with crutches. Other children smiled, but could not speak. CP had robbed them of their voice. My heart was breaking. I held my baby close and cried.

As parents of children with disabilities, we experience a grief that pierces the deepest recesses of our hearts. There's a pervading sense of helplessness, a sorrow beyond measure. God understands that kind of grief. He understood its heartache when His children, Adam and Eve, turned away from Him, ushering sin into the world. He felt its anguish when Adam and Eve grieved the loss of their son Abel at the hands of their son Cain. He endured its agony as He watched His Son Jesus suffer on the cross. You are not alone. God understands. He loves you, and He loves your child. Place your heart in His hands. Surrender your child to His tender care. His love penetrates the deepest pain. His love will lift you up. Through your child, God will bless you beyond measure. Your son, your daughter, holds a piece of God's heart that you will be able to see and know as few ever will. Pour your heart out to Him and He will be your strength.

Yours is a precious calling, for He has given you a very precious child.

Immersed in a New World

As I adjusted emotionally to what we were facing, I allowed myself to grieve and empowered myself with knowledge. I channeled my energy into being an advocate for my daughter. I researched cerebral palsy, neurologists, orthopedics, podiatrists, pediatricians, orthotic specialists, physical therapists, various surgeries and medical techniques, support groups, federal and state disability law, school programs and policies, social programs and social workers. I left no stone unturned. (See Appendix for a Resource Support link.)

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I learned that cerebral palsy is not a disease. It is a term used to describe a group of disorders that affect movement control. It can be caused by injury to the central nervous system before, during, or after birth.³ CP can also occur during infancy if there is damage to the brain within the first few years. It is similar to a stroke or head injury from a car accident. Danielle was diagnosed with spastic diplegia, a type of CP characterized by tense, contracted muscles affecting the identical part on both sides of the body.⁴

From the beginning, our weekly regimen included visits to the pediatrician, neurologist, orthopedic surgeon, and ophthalmologist, as well as home visits from the physical therapist, occupational therapist, and early education teacher. When Danielle was two and a half, I was strongly encouraged to enroll her in UCP's full-day preschool program. I didn't want to let her go. In less than three years, she had become the most consuming and rewarding gift that God had ever given me. How could I release her to the care of strangers? She was just a baby. But wanting the best for her, I researched the decision...and prayed. God comforted and guided me. I knew that He would be with her. And so, we walked hand in hand into our first special education classroom, scoping out this new and uncertain arena.

Danielle began UCP in the fall of 1987.

Finding Strength

As painful as it was, the label of cerebral palsy also brought ways of helping my daughter clap her hands, sit up, and eventually walk. It brought people with loving and giving hearts to console me, advise me, and support me. It brought children to my daughter's side who struggled as she did. How precious it is to see three-year-olds help and encourage each other in the face of adversity. It is a truly blessed sight.

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During a three-month hospital stay, following an eight-hour neurosurgery (a selective dorsal rhizotomy), Danielle worked through a rigorous and painful rehabilitation program. There were children in her ward who underwent similar surgeries. They came from as near as her own school at UCP and from as far away as Puerto Rico. There was a little boy who had been shot in the head during a street drug war. There was a little girl named Mercy who had cerebral palsy, was bound to a wheelchair, and could not speak. She had no hair: Mercy, recently diagnosed with cancer, was undergoing radiation therapy.

Mercy was nine. Danielle was three. The smile and joy on Mercy's face was priceless as she wheeled Danielle around on her lap, or as they listened to stories or music together. There is a strong sense of community and family when hardships bring people together. One person's struggle becomes the battle of many. One person's triumph is another's joy and hope.

Danielle had bicycle therapy every day as part of her rehabilitation program. We would put on her braces, strap her feet to the pedals, secure the padding around the center post to keep her knees apart (the spasticity in her legs drew her knees together), place her hands on adapted handlebar posts, and pull the tricycle with an attached string. When she learned how to steer better, we would push the bike from behind. Danielle did not have the muscle strength or coordination to push on the pedals with her feet to rotate the wheels. Her muscles were unable to receive the appropriate messages from her brain to coordinate the necessary muscle movements. So we trained her muscles and her brain by strapping and pulling and pushing each day.

Danielle loved riding. She also hated it. She wanted to ride a bike "all by herself" and was frustrated with her failures. She repeated her favorite Scripture verse over and over as she rode: "I can do all things through Christ who strengthens me" (Philippians 4:13, NKJV). Her friends cheered her on, "You can do it, Danielle!"

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One evening, strapped and ready to go, I pushed Danielle down the long and hollow hospital corridor. The little blue tricycle propelled easily across the polished industrial tiles. A few parents watched and cheered from doorways with their children. As I pushed, I encouraged Danielle to pedal. After several feet, I let go of the bike, as I did each night, hoping for a miracle. I stood still, tears streaming down my face, as Danielle pedaled that tricycle several feet more—*all by herself!*

When she came to a stop she said, “Mommy, push me. Why did you stop?”

Wiping the tears from my eyes, I called to her, “Sweetheart, turn around.”

“Mommy, why are you back there?!” she inquired.

I smiled through my tears. Other mothers cried. Danielle’s eyes searched from face to face, and with the most glorious childlike glee, she exclaimed, “Mommy, Mommy, I did it!” as her face broke out into tears of joy and disbelief.

That was a moment of triumph for us all. God had bound us together in love. If one child made it, we were all brought another step closer to victory.