



FOREWORD BY JONI EARECKSON TADA

Another Kind of Courage

God's Design
for **FATHERS** of
Families Affected
by Disability

Doug Mazza
& Steve Bundy

 **HEALTHY FAMILY SERIES**

PRAISE FOR ANOTHER KIND OF COURAGE

Hollywood can't create real heroes, but God does! Doug Mazza and Steve Bundy are two of them. They're stronger than Thor, more powerful than Iron Man, and more trustworthy than Captain America. These dads are the real deal. Their strength to navigate the wilderness of disability is inspiring. With wisdom and tenacity, they are finding victory in the battle. I am grateful to be learning from them.

Kirk Cameron

Actor, Producer of Inspirational Films
and Co-Host of *The Way of the Master* Television Series

This book brings fathers face to face with what we have to deal with, but in a loving way. It allows you to be honest without the guilt of thinking that you don't love your child. You can't deal with anything that you don't bring into the light of day. *Another Kind of Courage* helps you face things you need to face.

Calvin Johnson

Sole Caregiver of Two Sons, One with Severe Autism

The most endangered species in America is not the spotted owl nor the snail darter, but the responsible father. More children will go to sleep tonight in a fatherless home than ever before in our nation's history.

James Merritt

Pastor, Author of *What God Wants Every Father to Know*
and Host of *Touching Lives* Television Program

Doug Mazza and Steve Bundy have written a powerful testament of authentic fathering in their new book, *Another Kind of Courage*. Even if you're not a special-needs father, I strongly encourage you to read this book. If God has entrusted you with raising a child with a disability, you need to know that other fathers struggle with the same issues you do. I was profoundly moved by the stories in this book—they made me a better father and a better man.

Rick Johnson

Bestselling Author of *Better Dads, Stronger Sons*
and *That's My Girl: How a Father's Love Empowers and Protects His Daughter*

Another Kind of Courage

God's Design for **FATHERS** of Families Affected by Disability

Doug Mazza
& Steve Bundy



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D E D I C A T I O N

*To my wife, Lorraine, whose loving, simple invitation to church
led me to a saving knowledge of Jesus Christ,
and to my son, Ryan, who has suffered much, has taught much
and whose silent leadership is living proof that God's Word is true;
"My grace is sufficient for you, for my power is made perfect in weakness."
2 Corinthians 12:9*

DOUG

*To my greatest sources of inspiration:
my lovely wife, Melissa, who exemplifies "amazing" in every aspect of her life,
Jaron, who is every father's dream of a son,
and Caleb, who has taught me more about life, joy and suffering
than any textbook or sermon—without saying a word.*

STEVE

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We are grateful for a host of Joni and Friends Family Retreat directors and volunteers who minister to families affected by disability, providing much-needed respite and support. Only eternity will reveal the scope of your contribution. It has been our privilege to serve as retreat pastors and participate in discussion groups, where the unction for this book was born.

We would like to thank our dear friend Joni Eareckson Tada for her inspiration and the Joni and Friends board of directors for giving us an outstanding place to serve. As members of the leadership team, we have had the joy of serving alongside a talented and praying staff. As a result, we're even better fathers to our sons with disability. Keep up the great work.

Our sincere appreciation goes to senior editor Pat Verbal, whose contributions and skills have added so much to this book. She has been a steady force in helping us keep focused on writing in the midst of other responsibilities; without her, you would not be holding this book. Gratitude also goes to our literary agent and publisher Bill Denzel for his encouragement and to our gifted assistant editors Chris Ralston and Chonda Ralston. We also want to thank

Danelle Spatariu and Donna Rousseve for keeping us organized and moving forward.

Lastly, and most importantly, we praise our Lord and Savior Jesus Christ, who took on the form of an earthly man and walked the road of suffering to teach us how to live. He has never failed us in the darkest of nights and has been the light in our brightest days. He holds our children safely in his hands. Our prayer is that this book will inspire you to surrender to Jesus and discover another kind of courage—one rich in the promises of God.

Foreword

Before You Begin . . .

Not long ago, when my husband Ken was cleaning out our garage, he opened the kitchen door and held up a pair of Canadian crutches. “Do you want to dump these?” he asked. I glanced at them and got a lump in my throat. “Those are my Daddy’s,” I said softly. The aluminum was scraped and the rubber tips were scuffed, but the crutches brought into focus a flood of sweet memories.

Most memories harkened to the days my father would visit me when I was in the hospital recovering from a broken neck. With my life-altering injury, the Earecksons had suddenly become a special-needs family. It meant a complete change of family priorities and routines—and we were frightened. Facing a life of total and permanent paralysis, I was beginning to see how much I desperately needed Daddy.

Back then my father was in his seventies and had to use crutches because of his arthritis. I could always tell when he had arrived at the hospital and was coming to visit me—I could hear the heart-warming *click-click* of his crutches echoing up the hallway. *Oh boy, Daddy’s here!* I would think, anticipating his visit. My father’s presence meant more to me than I realized.

I was brand new to the world of disability, and it felt as though my life were spinning out of control; ripping apart at the seams; tearing apart into shreds. I wanted assurance—fatherly assurance—that somehow, some way everything was going to be *okay*. I remember my daddy picking me up when I was a little girl with a skinned knee and saying, “There, there, sweetheart, everything’s going to be okay; Daddy’s here.” *This* is what my father’s presence gave me.

When he held onto the guardrail of my hospital bed and smiled, I felt relieved; *Daddy's here. Everything's going to be okay.* It's what every child needs. Boys and girls with disabilities need a patriarchal figure who represents assurance. It's what dads do.

When a child is struggling with a disability—and his siblings are trying to deal with it too—a father becomes the symbol of stability and safety, of security and shelter. It's a tall order for any dad, and sadly, many are bowing out of the responsibility. For them a disability is simply too hard to face. Fathers today need guidance on how to develop “a long obedience in the same direction.”¹ They need help creating that intangible sense of assurance every family needs.

It's why special-needs dads require a special kind of courage. I once heard a rabbi say that our natural human inclination is not toward courage but toward fear, timidity, and cowardice. However, when men demonstrate bravery in the face of overwhelming odds, it impacts *everyone* around them—including their family. When dads courageously step up to the plate of a non-stop, 24/7 disability routine and stick with it for the long haul, courage rises in the hearts of *all*. Especially their children.

Maybe you've seen the movie *Braveheart*—the scene before the Battle of Stirling Bridge, when the Scots start losing heart because of the size of the English army that shows up. Fear, self-doubt, and intimidation look to win before anybody even strikes a blow. Then Wallace and his band ride up from the rear on horseback, faces painted blue. Simply their act of showing up gives heart to the Scots, and they take the field and win the day. Special-needs dads need to know that when they “show up” and become that patriarchal figure who represents authority and assurance in the family, *it wins the day*.

The book you hold in your hands, *Another Kind of Courage*, describes the remarkable journeys of two special-needs dads who are helping their families win the day. These two men take us step by step through the challenges of everyday life with a disability while

showing us how to bring stability and safety, security and shelter to the family. Let me briefly tell you about them.

Doug Mazza serves as president and COO of the Joni and Friends International Disability Center. Next to my own father, I know of no other dad who so tenderly and committedly cares for his family—especially his son Ryan, who has lived with Crouzon syndrome for over thirty-five years. Doug is *Braveheart* to Ryan—the kind of dad who constantly provides assurance that yes, with Jesus, everything will be okay.

Steve Bundy serves as vice president of our Christian Institute on Disability at our center. He and his wife, Melissa, parent two amazing boys: Jaron, who is typical, and Caleb, who has a chromosome deletion resulting in autism and other developmental disabilities. Raising Caleb is a joy, but a *huge* challenge. Caleb is no longer a little boy; he's a big, strapping teenager, and he keeps the Bundy family constantly on their toes.

These two men have my undying respect and admiration—I see their struggles, and I admire their valor. I wish every special-needs dad had the chance to sit long and talk much with Doug and Steve. And in a way, he can—*Another Kind of Courage* is an open book into the hearts of these men, revealing the kind of bravery that can help *any* dad win the day.

I pray that you will be blessed by the insights in this extraordinary book—and if *Another Kind of Courage* helps you to be a better parent to your own special-needs child, I encourage you to tell Doug and Steve. They'd be happy to hear from you, and you can always reach them through our website at www.joniandfriends.org/response.

Oh, and what did I do with those old crutches Ken found in our garage? Well, looking back on the way my own father influenced me—his daughter with a significant disability—there was no way they were heading for the trash bin. Those dusty, scarred crutches are hanging in our garage to this day, a constant reminder of the

shelter, safety, and fatherly assurance my own daddy gave me in my greatest, my most desperate time of need.

And I hope that you are able to give the same to *your* child.

Joni Eareckson Tada
Joni and Friends International Disability Center
Spring 2014

Introduction

“Don’t walk away!”

It’s the heartfelt plea of countless wives around the world—wives whose husbands struggle with accepting a child with special needs. It’s also the reason we wrote this book.

Real men don’t walk away—physically, emotionally, or spiritually. Real men seek ways to come to grips with their roles and responsibilities as husbands and fathers, even when the journey is not what they expected. Real men learn to live with *another kind of courage*.

We know this journey. As fathers of sons with disabilities, we both have traveled the well-worn path of the unknown and unexpected. We’ve walked where fears hide in dark places, nearly paralyzing us. We’ve also navigated the difficult course you find yourself on—the one that caused you to open this book.

We are the first to admit that we have not always made the best decisions. At times we’ve failed as husbands and fathers. Yet God’s love and grace have been utterly sufficient, and with his help we’ve also made some wise choices for our families. So we submit the following to you with a great sense of humility and with the hope that on these pages you will find the help you need.

Another Kind of Courage can be your companion and guide. It is filled with insights from men whose stories offer encouragement, strength, and hope—even humor. Laughter is like a refreshing stream encountered while walking along life’s dry and dusty trail. It gives us a moment to stop, rest, and refocus on life’s God-given treasures.

The good news is, you’re not alone! This uphill climb of coping with disabilities is filled with men who have gone before you and

are still climbing higher. They will point out to you where the loose rocks wait, and they stand ready to help you tie another knot in the end of your frayed rope.

How can a father embrace his own brokenness before embracing his child's? How can a man keep his marriage a priority in the midst of emotional turmoil? What does it mean to be the leader of the family when one's internal compass does not point to true north?

How does a man stay—when he feels like walking away?

Whether you are a first-time dad or have been parenting for years, *Another Kind of Courage* can help you become a better husband and father.

Doug Mazza and Steve Bundy

Courage When There Are No Answers

BY STEVE BUNDY

God enters by a private door into every individual.

RALPH WALDO EMERSON

Few things shake a man to the core of his being like hearing that his son or daughter has been diagnosed with a disability. Some men receive this news in a delivery room or doctor's office, others in the chaos of an emergency room. Still others hear words like "your child is not typical" during a parent-teacher conference at school and walk back to the car in shock, clutching pamphlets on special education services.

No matter where it's received such news hits hard. Even men of strong conviction and integrity can easily lose their way and become plagued by anger, fear, and depression. These fathers may question what they thought to be true about life. And men of faith may question how a loving God, who promised to never give anyone more than they are able to bear,¹ could allow such a circumstance

into their lives. The news hits every man differently but most experience a similar grief, similar pain, and find themselves suddenly with similar needs.

Nothing Prepares You

Dave Deuel, academic director of The Master's Academy International, had already experienced the joy of fatherhood with the birth of his first child. He and his wife Nancy were in the process of buying their first home as they prepared for baby number two. However, things didn't go as planned.

No one could have prepared me for the news. I had successfully finished school, gotten married, taken my first teaching job, and moved from one coast to another. Nancy and I were expecting our second child and anticipating a typical birth. When the moment of delivery arrived, the physician was hyper-vigilant. I remember wondering why he didn't lighten up a little. After all, births were supposed to be joyful occasions. But as our little girl entered the world, we began to realize this wasn't a typical birth. Our baby hardly made a sound. The look of panic on the nurses' faces and the deafening hush in the room sent a sick feeling to my stomach. When I eventually was allowed to hold our daughter, her skin was ash-blue, her tiny body limp and motionless. I watched as my wife slept peacefully, unaware of the growing reality that something was very wrong. That night I remember driving home numb, exhausted, and scared.

A growing number of fathers can relate to Dave's experience. The rate of children born with special needs is skyrocketing. The Centers for Disease Control reports that one in every 88 children born today in the U.S. will have some form of autism. Thirteen

percent of children ages 13-17 have developmental disabilities which can impair their learning, communication, and physical skills and abilities.²

Rick Copus, a worship leader and the founder of the Rick Copus Band, understands what fathers of these children will face.

I never planned on being a father at the young age of twenty-two. I was foolish and self-centered, with grand hopes for the future. But the night our first child was born with a disability, my life changed forever. And to make matters worse, as little Autumn lay in the hospital's neonatal intensive care unit in a fragile state, our house was being burglarized. I couldn't believe it. I returned home to find that thieves had ransacked our belongings and taken many of our most valued possessions. It suddenly hit me hard that nothing I dreamed about for my life was going to come true. In the early months, I just did my best to care for my wife and daughter, keep my job and hold my emotions together so no one would detect how frightened I really was. Soon Autumn began having grand mal seizures, and the hospital became our second home. Our lives turned into a continuous roller coaster ride.

Who will stand beside men like Dave and Rick to assure them that even in their darkest hour God is still there? Too often, family and friends don't know what to say, and their looks of pity make parents of children with disabilities want to hide. When courage seems lost, these fathers need a friend who can open their eyes to the sovereignty of God's grace and his power to transform even the most difficult circumstances into times we can celebrate God's goodness and experience his joy.

For over a decade, I've been called to stand in that place—not only as a pastor and disability ministry leader, but as the father to a son with multiple severe disabilities. Like Dave and Rick and every other father of a child with a disability, I have asked the same

gnawing questions that steal a man's sleep. In my desperation, I've wrestled with God as Isaac's son Jacob did and begged God not to let me go until he had changed me.³

If this is your story as well—if you are a father wrestling with these difficult issues—you need to know that you are not alone. In this book, you'll meet other fathers who have faced the very things you are facing today and are here to stand with you. Our desire is to offer you a reason for the hope that we have found in Christ Jesus, for our children and our own lives.

I am certain that you have many questions. And while we don't claim to have all of the answers, we acknowledge that no question is insignificant. That includes the question I fielded one Sunday morning from one of my youngest inquirers—my son, Jaron.

Daddy, How Big Is God?

It was just the two of us that morning, me behind the wheel and my four-year-old son Jaron in his seat, staring at the scenery as we drove to church. Most Sundays there were four, but that day Caleb, our older son, was ill and my wife, Melissa, kept him at home. I might have joined them had I not previously committed to help in our church's disability ministry. So it was just Jaron and me cruising to church.

Like most children, Jaron had the uncanny ability to ask simple questions with enormous implications. That day he simply asked, "Daddy, how big is God?"

Wow! What a question from a child who had yet to spend a day in kindergarten! A sense of pride ran through me. I felt delighted that Jaron had God on his mind. Maybe I was doing something right as his father.

In graduate school, I had picked up a skill that served me well. When uncertain as to how to answer, or when time is needed

to think, I answer a question with a question. Since Jaron had caught me off guard, I resorted to this technique.

“How big do *you* think God is, son?”

Jaron did the natural thing for a child trying to comprehend the “bigness” of God. He looked for something he could use as a comparison. Through the window, he could see the rugged San Gabriel Mountain range a short distance away. They were a familiar sight, green in the spring and blanketed in snow during the winter. Mount San Gorgonio rises to a height of 11,500 feet. “Is God bigger than the mountains?” he asked.

“Yes, Jaron,” I said, “God is bigger than the mountains. In fact, he *created* the mountains.” I reminded him of the creation story he had heard in Sunday school and conjured up as many word pictures as I could to help his young mind grasp the difficult concept.

“How big is God?” It’s a simple question with a complex answer. It’s also a question asked by fathers of children with special needs—fathers like you and me. Like Jaron we often compare God to the biggest visual we can find. Our minds are drawn to the apparently devastating life circumstances of our children. The questions buzz in our heads: *If this God is so big, can’t he fix every disability?* Better yet, *Why doesn’t he prevent them in the first place?*

Is God really a mighty fortress to be reckoned with, or just a crutch for old ladies to lean on? Where is this God of all the earth who through his spoken word called all creation into existence?

I have asked those questions over and over again. They have come to me in the darkness as I lie in bed, in the daylight as I go about my work, and in the artificial light of hospital hallways where I’ve paced for hours. They take up residence in my mind just like they do in yours. You’ve probably learned, as I have, that while questions are plentiful, sometimes answers seem few and much too elusive.

My Story

My son Caleb was born with a partial chromosome deletion, and I have to admit that my view of God changed and was even shattered the moment I heard the news. Like fathers everywhere, I had high expectations for my son. I had looked forward to the small things in fatherhood that make life grand: first words, first steps, first game of catch, first day of school. My mind had often fast-forwarded to my boy's graduation, his first car, even to the day of his wedding.

That was before I heard the words "partial chromosome deletion." The more the doctors explained medical terms, the more my world felt like it was unraveling. We men can endure anything but helplessness. It's not part of our wiring. We want to fix things and make our family's world right and safe and joyful. What the doctors told me took away all those opportunities. There would be no fishing trips, no learning to bat a ball, no sprinting for a touchdown. There would be no teaching my son about life by passing down my years of experience. For Caleb there would be endless disability. The prognosis dissolved my dreams and hopes for him as I had understood them. And that wasn't the end of it. Caleb's disabilities would later include severe global delay, low muscle tone (hypotonia), autism, and a string of other medical complications.

Interestingly, before Caleb's birth I worked with adults with developmental disabilities while I attended seminary. My wife and I had dedicated our lives to world missions and had already spent some time on the mission field, where many of the people we worked with had disabilities. Looking back, I wonder if this was divine symmetry preparing us for the life we would lead with Caleb. On the other hand, we belonged to a denomination that held the belief that children like Caleb were not born to believers like us. It seems silly to say now, but many religious people continue to believe this to be true.

To understand what a difficult transition it was for me to become the father of a child with special needs, let me emphasize that the news about Caleb's condition completely contradicted what I believed at the time. My world seemed to sway and tremble as I tried to reconcile how God could allow such a thing to happen to someone like me, a faithful follower. Most of our friends believed the same things we did, so consequently, they were ill-equipped to give us the comfort and ministry we needed, right when we needed it most. Truthfully, I hardly knew how to comfort myself. Well-intended friends let us know that they were praying for Caleb's immediate healing and would stand with us for increased faith. Some even counseled us that we had to resist the devil because he had stolen my son's health, and we had to reclaim it from him. And there was the constant encouragement to confess and claim healing for our son lest we "confess a negative report" and cause our son to remain like this for the rest of his life. I believe we and these friends were zealous and sincere in our pursuit of God's best, but suddenly my family's situation did not match my beliefs. I found myself forced off the predictable path I had so confidently followed.

The Problem with Men

There was another problem: I am a man. There are a few things no man can stand, and heading the list is being told he is lost. How many times have husbands and wives had the same old argument, with the man refusing to ask for directions? *Don't tell me how to get there, I can figure it out. Whoever put up these stupid road signs must have been on drugs. Leave me alone! I'm not lost, and I don't need help.*

But I *was* lost. Emotionally lost. Spiritually adrift. There were days when the man in the mirror appeared as a stranger with only a vague resemblance to me.

Loss of control paralyzed me, as it does most men. We want to be in control of everything. It's why we love the television remote control. Just a click of a button and presto, I control the world of TV with hundreds of channels at my beck and call. We men need it. It's what makes us strong, driven, and ambitious—or so we think. A child's disability strips all control from our hands.

It can also attack one's manhood. Say the word "manly" to most men and images of Russell Crowe in *Gladiator* or Mel Gibson in *Braveheart* come to mind. For most men, words like "manhood" and "weakness" don't even belong in the same sentence. It's like a javelin to the heart of our male ego to have a child with disabilities because there's nothing we can do about it. In those early days, doubt crowded my mind. *What kind of a man am I? How could such a weak offspring come from me? What went wrong with my sperm?* Men who have children without special needs have a hard time understanding how difficult it can be to reconcile your manhood with the apparent weakness of the child before you.

Greg Schell, director of the Washington State Fathers Network and the father of a 33-year-old daughter with Down syndrome, believes the issue is that men are socialized in a very different way than women, which often leaves them less prepared to handle a child's disability. "Men learn from an early age that they must be tough when the chips are down. They're encouraged to 'suck it up' and to fix any problem that comes their way. But when they learn they have a child with special needs, they face a dilemma when they realize that even the smartest minds in the world can't change this new reality."⁴

These hurting men are yearning deep inside for someone to tell them that they did nothing wrong. When Caleb was born, I longed to hear the affirmation, "You did **not** do anything **wrong!**" But those words did not come until much later.

Reality Is Not an Option

When my friend John received the news that his unborn daughter would likely not survive past twenty-five weeks in the womb, he was forced to face a grim reality. The only two options the doctors offered were to allow the child to die in the womb or to perform a C-section, which his daughter might not survive. If she did survive, she would most likely be profoundly disabled.

As John grappled with the weight of this decision, he and I prayed together, shared truths from God's Word, and cried. Afterwards, John asked me to write down some of our discussion. Here is an excerpt from the letter I sent him:

February 4, 2007

John,

I want to thank you for sharing your raw feelings with me, which is never easy, and let you know that your feelings are completely normal and natural. Although I don't exactly know what you're going through, my journey has been fueled with similar challenges and I relate to your fears and concerns.

First, let me say that your daughter is very well cared for and loved by God, as are you and Julie. Regardless of the dire scenarios you have been given and of those running through your mind about the life of your daughter, remember she is precious in the sight of the Lord.

At the risk of sounding overly spiritual, I encourage you to really ponder this thought. It may be the one thought that gets you through some difficult times: God loves and cares for your family! God is in control in your out-of-control circumstances. He will meet you at your point of need and provide the grace you need to be the

husband and father you long to be. He has not abandoned you, nor punished you for some known or unknown sin. It doesn't seem like it now, but your family's future is bright and promising! God called you. God gave you Julie as your wife, and God gave you your daughter. Blessed be the name of the Lord.

Unfortunately, bad things happen in life, and it sucks! No one can ever answer the "why my child?" question. Because of the fall of Man (so I believe), things go wrong—sometimes very wrong. And God allows suffering, but we must choose how we will respond. You, my friend, may walk through this fire, but you will not travel alone.

Wow! That sounds so religious! You're probably thinking, "What garbage! Where is God in this? I just want a healthy daughter." I do understand!

Yet I wish someone had come alongside of me when Caleb was born to reassure me of who I was as a man, a disciple of Christ, a husband, father, and leader—to say that it was going to be all right and that God was still pleased with me. No one did, and you know my journey.

Your daughter may be perfectly fine, and Julie may carry her long enough for a healthy delivery! This is my prayer for you! But the prognosis at this time is not favorable, and I am not going to sugarcoat anything. Life for parents of children with special needs is difficult; for some more than others.

I can't deny that not a day goes by that I do not wish Caleb were "normal." And some days I feel tremendous anger at God for Caleb's condition. That's right—anger. Some days my anger is really about myself and my pride. To say that having a child with a disability is inconvenient is an understatement—it is consuming in every possible way.

I must also admit, however, that no day goes by that I don't thank God for Caleb. I love him with a deep passion and his life has taught me more about living, laughing, crying, suffering, sin, and victory than any other person I've ever met. And every night I say a prayer over Caleb. I watch him sleeping in his bed and remind myself that God's love and grace are greater than I can ever imagine and the mystery of life and death are beyond my grasp. I am utterly and fully dependent on God.

We don't need to discuss the sanctity of life, human dignity, purpose, and the meaning of life. Intuitively, you know your daughter needs a father who will fight for her to the end; one who believes her life is as valuable as any other, regardless of her disabilities and limitations. I'm sure you struggle to justify having an immediate C-section with the understanding that the baby will likely not survive and go home to her Heavenly Father. You may think this would be better for her than living with the disabilities. Chances are your next child will be healthy, right? But it's not so easy.

Your daughter is actually God's daughter. She is God's first and yours second. She is in his image first and yours second. Let that sink in. Everything you believe in and have stood for will be tested by the circumstance before you. Your daughter may be born with severe disabilities that will forever change your future, forever alter your view of what it means to have a family, take vacations, go for a walk, pay for ballet lessons, and all the stuff you dream for her. This can turn you upside down and inside out. Not only will you have to face the great disappointment of not receiving the child you expected, but you must face the challenges of her disabilities.

So, I write with no pretentious illusions. I offer no, “Oh, what a blessing from God. His grace will be sufficient. God chose you because he knew you were the right couple for a special needs child.” Well-meaning people with no understanding of disabilities don’t know how ridiculous that sounds to parents struggling to cope with their child’s diagnosis.

Still, we have many good days and joyful times with Caleb. Our family has developed deep, intimate relationships because of our journey with him. Melissa and I look at life and the world completely differently than before. Despite our shortcomings, we feel closer to God and to one another. Our ministry to others is deeper. We’ve suffered and can empathize with people in a greater way. God uses our brokenness, and I wouldn’t change this.

The way forward on this difficult journey is always uphill, but it’s still forward. I love you, my friend, and am here for you! I’m praying for you.

Steve

John and Julie made the decision to have their baby delivered by C-section, giving their daughter her only chance for survival. The following days were filled with exhausting medical decisions and heart-wrenching choices made with no idea what the outcome might be—all done in an effort to give their daughter a future and a hope. Four days after her birth, their daughter went home to be with the Lord.

It is during such times that the real questions begin, that a man’s world seems to go upside down, that a man realizes what minimal control he has over life—his or that of his family. But it is also a priceless opportunity to see life, and ourselves, in a truer light.

What Is True Manhood?

In the book of Philippians, the apostle Paul talks about the change that Christ brought in his life of self-confidence and self-righteousness. Before knowing Christ, Paul placed his confidence solely in his abilities, his education, his strength; he felt in control of his world. However, as he experienced suffering and brokenness, Paul discovered that his manhood was not based in his strengths, but rather in his weaknesses that were made strong through faith.

True manhood looks nothing like the strong, self-capable men displayed in Hollywood movies or men's magazines. When it comes to pulling your world back together, there is no "four-step" formula. As Christian men, our manhood must take on a new image that moves from self-confidence and personal success to complete dependence upon God.

Men are compartmental thinkers. We like each area of our lives tucked in its place, easy to find, easy to use. This allows us to deal with one thing at a time instead of being overwhelmed by life's many parts. Sensory overload occurs when we mix up the various compartments. For example, when I watch television, I'm in my mental "TV compartment." That's my TV room, and I like it to stay that way. I don't like to watch TV, play with my kids, and talk on the phone at the same time. Women don't always understand this. It frustrates my wife when I don't turn my head to talk while I watch television. Women don't understand that many men are incapable of being in the "TV compartment" and in the "talking to my wife with full attention compartment" at the same time. Because we men can't do both at the same time, something suffers—and unfortunately, it's usually the wife.

Likewise, we often create a compartment for God. We think we have him pretty well figured out. That is until life becomes messy and our compartments begin to collapse into each other. God, as we thought we knew him, no longer fits our expectations. He has left his box. In fact, not only has he left his box but God has spilled

over into all the other compartments of our lives. We no longer control him or how and when he intervenes in our lives.

Remember Jaron's question . . . How big is God? The answer: Much bigger than we can imagine!

While we tend to focus on what God is *not* doing for us and our child, God *is* at work protecting and keeping our lives in his care. He constantly demonstrates his grace to us even when we shake our fist and demand an explanation for our child's lot in life. He prepares others to comfort us while we run and hide, sometimes resorting to harmful vices like pornography, alcohol, or sex to try to ease our pain. God stands ready to restore us to a right relationship with him even though we feel like turning our backs on him.

God doesn't belong in a box. Instead, we need to allow him free rein to help us navigate the challenging waters of our child's disability.

Looking with God's Perspective

Your child is no accident. God is not sitting on the edge of his throne biting his fingernails hoping that everything will be all right. The struggles, challenges, hardships, and pain you and your family experience are not beyond God's control. He knew your child before he or she was formed in the womb.⁵ Scripture says all things, including people, were created by and for God.⁶ God created man in his image, which speaks of each individual's inherent worth and dignity regardless of abilities or functions—the things we usually focus on. A fellow-struggler in the Old Testament named Job said of God: "You clothed me with skin and flesh, and knit me together with bones and sinews. You have granted me life and steadfast love, and your care has preserved my spirit" (Job 10:11-12, *NRSV*).

Our society usually focuses on the physical. We celebrate athletes and beautiful people. When we meet someone, our first judgment

is based on appearance. But people are so much more than their physical veneer. Every individual has a spiritual component called a soul. The body ages, grows weak, is subject to disease, and ultimately dies. No one leaves this life alive—at least not physically. The soul, however, lives forever. The apostle John wrote a letter to his friend in a distant church saying, “Dear friend, I pray that you may enjoy good health and that all may go well with you, even as your soul is getting along well” (3 John 2).

Did you catch that? He prays for the person’s body *and* soul.

Children with disabilities have souls that are as vibrant and alive as any person without a disability. Your child, no matter his or her special need, has a soul that cannot be damaged by missing or misaligned chromosomes.

God’s Gift of Emotions

King David of the Bible has always captivated me. Here is a man who experienced just about every emotion one can imagine. Fortunately for us, those emotions were written down in the Old Testament book of Psalms for the world to see. David freely expressed his hatred, love, greed, lust, sorrow, joy, confusion, and faith. Though most men won’t admit it, we are emotional creatures. We just don’t show it because we’ve learned to press down worry, dilute fear, and ignore all the emotions we don’t like. Disability changes that. Disability teaches us, even forces us, to experience and express the full range of human emotion, like David did.

Many of us think emotional displays (other than anger) are weaknesses reserved for women. Let’s be clear—this idea is nonsense. All humans are emotional beings. Sure, we express our emotions differently than women, but they are there and just as real.

No doubt you’ve ridden the roller coaster of emotion—hopeful one moment, utterly despairing the next; confident one day, ready to give up the next. Your feelings are normal. You are not alone!

You have a right to be emotional when there are no answers for your child's special needs. But you don't have a right to give up. **Elohim, God Our Father**, is present in every situation you face. He is all-knowing and all-powerful even when you can't understand his purposes. David reminds us of this in Psalm 46: "God is our refuge and strength, an ever-present help in trouble. Therefore we will not fear, though the earth give way and the mountains fall into the heart of the sea . . . The Lord Almighty is with us."⁷

The Bible is the well I go to when my emotions begin to overwhelm me. God's promises refresh and support us in difficult times. For example, 1 Peter 5:7 says, "Cast all your anxiety on him because he cares for you." This verse says we can toss off our anxiety. Imagine the powerful spin of an Olympic athlete as he hurls a 17-pound shot put more than 70 feet into the air. What a thought! We are told to take our worries and throw them on God. He doesn't mind. He actually invites it.

That verse also reminds me that I am not alone. I am not casting my care to the wind or writing it on a sticky note for later. Instead, I am casting it upon God. He can handle it. He's got big shoulders. If I leave it with him, I know it will be taken care of—even if the outcome is not what I expected.

Finally this verse assures me that God cares for me *and* my child. This promise is not just for me, but also for those under my covering who cannot speak for themselves. No problem is too small for God to notice or too big for him to handle. God cares for my family. That gives me great peace and confidence.

There is no shame in facing our emotions. The mighty warrior king David wept. Jesus wept—several times.⁸ Do we think we're stronger or manlier than David or Jesus? There is no shame in expressing our emotions. While it's true that much of the burden of strength in a family falls to fathers, dealing with the pain we feel doesn't prevent us from being the steel our families need.

God's Grip Holds

When disability strikes and questions mount, we feel a loss of control. But our loss of control can be a blessing in disguise. The truth is that we were never really in control in the first place. None of us can control whom God places in our families, or what the future will look like, or the emotions we'll feel. Man certainly has never controlled God. Thinking we are in control of our own lives is just an illusion and having a child with a disability destroys that fantasy. In reality, true contentment only comes when our illusions of control are replaced with this truth: *God is never more in control than when we feel out of control.*

Dave and Rick, who you met earlier in this chapter, had much to learn about giving God control of their lives and families. As they did, the Light⁹ began to dispel their darkness.

Dave Deuel

The day after Joanna's birth, the doctors said, "Things are bad. She may not live. If she does, she may have brain damage." My legs buckled and my mind cried out, 'Lord, where are you?' After waiting two weeks, the chromosome tests were thrown out due to contamination. We didn't want to put our little girl through testing again. My heart ached, but familiar verses wandered into my thoughts . . . Children are a gift from the Lord¹⁰. . . Take delight in the Lord, and he will give you the desires of your heart.¹¹ What I desired was a healthy and normal baby. These verses were not working for me. The confusion was overwhelming. In the darkness, life seemed to be over.

But life was not over. I know now that a bright new day had dawned for my entire family, although it would take a while for us to fully recognize and accept it. God's grace would soon ease the pain and lift the darkness in ways we couldn't have dreamed of at that time.

Rick Copus

The first five years of Autumn's life were filled with medical challenges. The exhaustion and stress led to several job losses and even a divorce. As a single dad of a child with cerebral palsy and quadriplegia, my loneliness was incomprehensible. I turned to drugs and alcohol to cope, but soon realized I was living on the edge and needed to change. In my daughter's smile, I knew God was there. I thank him for giving me the ability to focus under pressure and to eventually turn to a spiritual fellowship. There I gave my life to Christ as my Lord and Savior. That's when everything in my life and my family began to change for the better. Autumn never let her physical condition get her down and her perseverance taught me to keep going even when it seemed impossible. In my new life I met a wonderful woman who joined me in living a life affected by disabilities. God has forgiven much in my life and redeemed me for his purpose.

God Is Big Enough

Just as my son Jaron pondered how big God is, you probably have as well. I've discovered that God is big enough to know our needs, feel our hurts, understand our disappointments, sense our fears, notice our mood swings, sympathize with our concerns, and empathize with our pains.

You've been through the wringer, my friend. You've been pressed, crushed, and kicked around by circumstance. Most likely, you've blamed yourself for events you couldn't control. But in it all, know that you are not alone. There are many of us in the "Brotherhood of Wounded Fathers." I didn't start the fraternity—I didn't even choose to join it. Neither did you, but here we are, members nevertheless. It helps to know that there are others like us. It's comforting to realize that others understand my pain—your pain. The one thing that

makes the most difference in my daily life is to believe that God is big enough to overcome any problem my family might face.

You may look at your child and say, “It’s unfair.” But God never promised that life would meet our standards of fairness, only that he would be there in the middle of our crisis when we humbly come to him. He is the Answer when there are no answers. And his grace does not fail.

“ . . . as a father deals with his own children, encouraging, comforting and urging you to live lives worthy of God . . . ”

1 THESSALONIANS 2:11-12

GROWTH STEPS

1. God is not surprised by disabilities. It is okay to ask God the hard questions.

What is your question for God today?

2. In times of crises, God has something important to say to you.

What has God said to you today through this chapter?

3. *Elohim*—God My Father is all-powerful, all-knowing, and is present with me in every situation.

Read Deuteronomy 6:4-5 and use it as your daily prayer.

Another Kind of Courage

STUDY GUIDE

Chapter 1

Courage When There Are No Answers

It is natural for fathers of children with disabilities to wrestle with feelings of depression and isolation. Questions over suffering and trusting God in the midst of it have plagued men since the Fall. Admittedly, it's easy to feel lost at times. Younger fathers may worry that they lack role models to guide them in being a father to a child with disabilities. Some dads may be concerned about how they will provide for their wives and other children, while walking the mine-field of special needs. Single fathers are often overwhelmed by trying to be both mom and dad while keeping a full-time job. But God never leaves us alone to work through the maze of medical, social, and emotional issues that we face on a daily basis! God is *bigger* than the nagging confusion we experience. He is ever-present, providing constant companionship as we travel this uncertain path of disability.

Discussion Questions

1. What scares you the most about your child's disabilities? Who or what has helped you deal with your anxieties?
2. God invites you to trust him, recognize his work, and believe that he will answer your prayers and meet your needs. What are the desires of your heart? Proverbs 3:5-6
3. What does 2 Corinthians 12:9-10 tell you about the connection between manhood, strength, and weakness?

Action Steps

- **Head** – My beliefs about God shape how I live. I will examine my faith's impact on my relationship with God and my family.
- **Heart** – When my dreams appear to be crushed under the load of disabilities, I will trust God's righteousness and let him carry my fears.
- **Hands** – I will spend time with like-minded friends to support our mutual beliefs and grow deeper in our faith.

For Group Leaders

Some men don't enjoy talking about themselves and their needs. Open this session with a humorous story about your own father or children. Invite others to chime in with their stories. Assure group members that there is no pressure to discuss their feelings. Strive to create a safe place by encouraging a respect for confidentiality. Acknowledge that fathers may be in different stages of parenting, and their children may have various disabilities ranging from mild to severe. Observe how the men in your group relate to disabilities in different ways and point out common experiences.

For Further Study

- *Why, O God?: Suffering and Disability in the Bible and the Church* by Larry J. Waters and Roy B. Zuck (Eds.). Wheaton, Illinois: Crossway, 2011.

Endnotes

Foreword

1. *A Long Obedience in the Same Direction* is the title of a book by Eugene H. Peterson first published in 1980.

Chapter 1

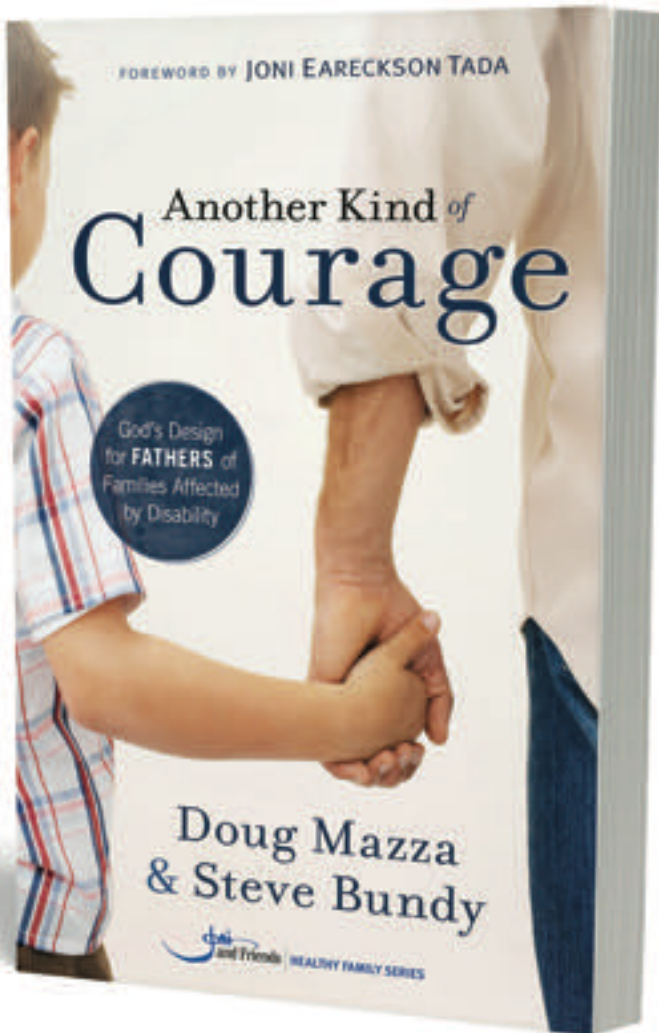
1. See 1 Corinthians 10:13-14.
2. See www.cdc.gov/ncbddd/autism/data.html.
3. See Genesis 32:9-12.
4. Jacqui Goetz Bluethmann, "Dads Dealing with a Special Needs Diagnosis in their Kids," *Metro Parent*, <http://fathersnetwork.org/wp-content/uploads/2012/10/Connections-summer-2012.pdf>.
5. See Psalm 139:13-14.
6. See Colossians 1:16.
7. See Psalm 46:1-2,7.
8. See 1 Samuel 20:41, 30:4; Luke 19:41-44; John 11:35.
9. See John 8:12
10. See Psalm 127:3, *NLT*.
11. See Psalm 37:4.

About the Authors

Doug Mazza, former President and Chief Operating Officer of Joni and Friends, has oversaw an explosive era of growth in ministry and program expansion since coming to Joni and Friends in 1999. Applying his award-winning expertise and skills in corporate leadership, after serving as senior executive for American Suzuki Motor Corporation and Hyundai Motor America, Doug took the vision of Joni Eareckson Tada and helped create all that Joni and Friends is today – the authoritative voice on Christian outreach to the world’s one billion people with disabilities and their families. Ministering to his son, Ryan, through more than 30 years with severe disabilities, Doug Mazza brought a warm and personal perspective to the development of every program at Joni and Friends.

Steve Bundy is Senior Vice President of the Joni and Friends Christian Institute on Disability. He was a contributing author to *Life in the Balance: Biblical Answers for the Issues of Our Day*, and co-executive producer with Joni Eareckson Tada of the Telly-Award winning television episodes, “Making Sense of Autism: Myths That Hide the Truth” and “Truth for the Church.” Steve is an adjunct professor at California Baptist University and lectures on disability ministry at educational institutions and conferences around the world. He frequently appears on “Joni and Friends” television episodes and national radio, and has written articles or been interviewed for *Christianity Today*, *Charisma Magazine*, *Focus on the Family* and others. Steve and his wife Melissa know firsthand the joys and challenges of parenting a child with special needs, as their own son, Caleb, was born with a chromosome deletion which resulted in global delay and a secondary diagnosis of autism. Steve holds a B.A. in Theology and Missions and an M.A. in Organizational Leadership. He is a licensed minister and has served as a pastor and missionary.

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