



A Compassionate Guide
for Families Living with Disability

Real Families, Real Needs



Joni and Friends

FOREWORD BY **JONI EARECKSON TADA**

If we discover, in Heaven, an extended Hebrews 11 “Faith Hall of Fame,” I fully expect Joni Eareckson Tada to be on the list. Joni and Friends’ new book, *Real Families, Real Needs*, is an amazing source of strength, wisdom, and encouragement for families living with disability.

KIRK CAMERON

Actor, producer, and cofounder of Camp Firefly, a camp for seriously ill children and their families

Real Families, Real Needs accomplishes what very few books for families of kids with special needs have done before: It addresses the needs of all family members who love a child with special needs. The first four sections of the book speak specifically to the unique needs of dads, moms, siblings, and grandparents. The final section helps parents become effective advocates and provides ideas others can employ to support parents and families. With wisdom founded in experience, the authors speak directly to the hearts of family members and meet them at their points of need. I highly recommend it!

JOLENE PHILO

Author of *A Different Dream for My Child* and parent of a child with special needs

As a parent to kids with disabilities, I’m not interested in “all roses” stories that gloss over challenges. This book doesn’t do that. Rarely have I come across accounts from real families encompassing the difficult and beautiful journey of special needs, all while pointing the reader to Christ. Everyone needs a copy of *Real Families, Real Needs* on their bookshelf.

GILLIAN MARCHENKO

Author of *Still Life: A Memoir of Living Fully with Depression* and *Sun Shine Down*

The words were blurry . . . due to my tears . . . but the messages and testimonies are clear. Thank you to the many contributors here who allow us to humbly walk a bit with them on this sacred journey.

TOM VANWINGERDEN

Executive director, Friendship Ministries

Countless hurting people have been helped by the ministry of Joni and Friends over the years, and their new book, *Real Families, Real Needs*, is no exception to the quality of comfort they offer. As a psychologist, I know all too well the nature of the emotional suffering experienced by families with disabilities; and having grown up in one myself, I know these needs from the inside out. The courageous and thoughtful approach to addressing the needs of fathers, mothers, siblings, grandparents, and family members is both spiritually and psychologically sound. I could refer my clients to this book with complete confidence that they will find emotional help, and I plan to for many years to come.

MARK W. BAKER, PHD

Executive director of La Vie Counseling Center and author of *Jesus, The Greatest Therapist Who Ever Lived*

This book is helpful at many levels. In each of these chapters, there are stories of real people who are facing tough circumstances in families affected by disabilities. Through these stories, it becomes clear that God, the Creator of the Universe, loves each of us regardless of performance, abilities, or perceived holiness. God accepts us—not because of our worth or goodness but because of His love and goodness. In the midst of lives and families affected by disabilities, Jesus is making Himself known in amazing and personal ways, bringing great comfort. In the midst of life-changing diagnoses, we can choose fear and focus on our shattered dreams and numerous unknowns, or we can

choose to trust God and believe that He is in control of every unknown. This book offers hope and many practical suggestions for moving in a positive direction toward life with Christ. I hope as you read it you will find help and hope in your journey.

PAMELA A. HARMON

Vice president, Young Life Capernaum

In February of 1998, the Ware family entered a world that we had heard, prayed, and read about but were personally detached from. When our son became a quadriplegic through an accident during basketball practice, our entire family was changed forever! We found ourselves facing multiple issues (e.g., emotional, financial, medical, spiritual, and living space) for which we were not prepared. We became intimately associated with a cultural group—families with disabilities, whom we had previously known only from a distance. Resources from a Christian perspective are needed for the encouragement and education of families with disabilities and those who live and serve with them. *Joni and Friends* has been providing encouragement and enlightenment to families with disabilities and those who serve with them for decades. *Real Families, Real Needs* is a timely, practical, and encouraging resource!

DR. A. CHARLES WARE

President, Crossroads Bible College

As a father who has faced tragedy in my family, I find *Real Families, Real Needs* to be authentic, practical, solid, biblical, and gritty. From the first page, tears welled up in my eyes as I read story after story from men and women facing what I've faced. If you are walking through that valley, you will want to take this book with you.

DAVID LYONS

International vice president of The Navigators Worldwide and author of *Don't Waste the Pain: Learning to Grow through Suffering*

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People's names and certain details of their stories have been changed to protect the privacy of the individuals involved. However, the facts of what happened and the underlying principles have been conveyed as accurately as possible.

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Foreword



WHEN I BROKE MY NECK in a diving accident and suddenly became a quadriplegic, I felt as though God had walked into the room and upset the puzzle table. Not that I had everything figured out; it's just that before my accident, I figured my future would be a simple process of putting the puzzle pieces of my life together, all nice and orderly. I was looking forward to seeing my life picture easily fall into shape.

It's what most of us wish for our lives. But when your husband barely survives a debilitating stroke, or your elderly parent sinks into dementia, or your daughter breaks her back in gymnastics tryouts, or your baby is born with a genetic

disorder you can't even pronounce, you feel as though God has thrown your family's puzzle against the wall.

You frantically scramble to locate the missing pieces, quickly solve the problem, and get your family back on track. But over time, you realize some key puzzle pieces are lost, and others simply don't fit anymore.

We hate it when life isn't fair! We expect our families to have the good life, with long stretches of ease and comfort and only occasional interruptions or irritations—frustrating, but easily bearable. Nothing bursts that bubble more quickly than a disability. A serious disabling condition is always a life changer for individuals and their families. Whether through stroke, a diagnosis of muscular dystrophy, or the loss of a bright and happy mind, we're suddenly awakened to the fact that life will never be the same.

It reminds me of my friend Susan who, when she learned that the child she was carrying had multiple disabilities, collapsed into her husband's arms and sobbed, "Our lives will never be the same! Never!" Brad held Susan tight, stroking and kissing her hair. Then he whispered, "Sweetheart, maybe our lives aren't supposed to be the same. Maybe God wants it that way."

Those were wise words. God has wired life to be difficult. Inconvenient and unwanted upheavals to our plans are part of what it means to live in a broken world. It's a jolt to find that life is not the bed of roses you or I anticipated. But it's necessary. And personal growth means learning how to deal morally and compassionately with these interruptions. Change potentially stretches the soul.

But here's the challenge: A disability can either bless a family or rip it apart. The choice often lies with us and the way we approach a family member with a chronic condition.

Will we remain hands off, or will we dare to roll up our sleeves and get involved? Will we play the blame game, or will we love full throttle? It's why the message in *Real Families, Real Needs* is so important. Whether you are a parent, grandparent, sibling, or other relative, this book will help you understand how a life-altering disability can and should draw your family closer to God and to each other.

God has placed disability in your family's midst so that everyone's life might be touched and changed. Disability has a way of pressing everyone up against each other—it's uncomfortable but necessary. Families would not have such significance if they did not, in fact, give us claim upon each other. And often it's the disability which creates the moral community that deserves to be called a family.

So, put the puzzle pieces away and fold up the puzzle table. God wants you to move beyond your urge to figure everything out and understand "how it all fits." Lean hard into His grace, and thank Him for the book you hold in your hands. Absorb the insights and life experiences of the fellow sojourners you'll meet in these pages. Put the principles to the test in your own family. And you'll find that change isn't as scary as you thought.

Two final words. First, you can trust the authors and contributors. Pat Verbal is a seasoned caregiver who spent the past ten years caring for her precious husband with Alzheimer's disease and her elderly mother. Both went home to heaven in 2017. Steve Bundy is the father of a teenage son with autism and physical disabilities. Neither Steve nor Pat are "textbook technicians"; rather, they are caring and compassionate family members who are intimately acquainted with the nonstop, 24/7 routines of never-ending disabilities.

Second, I'd like to extend a special thanks to our friends at

Focus on the Family who, like Joni and Friends, are dedicated to helping your family through prayers, resources, and practical support. It is my prayer that this remarkable book will be passed around to sisters, brothers, grandparents, spouses, aunts, and uncles. May every member of your family, young and old alike, be blessed, inspired, and motivated to welcome the change that God has brought into your midst through a disability. Yes, you can welcome that change . . . it's what family love is all about.

Joni Eareckson Tada
Joni and Friends International Disability Center



PART 1

A Father's Courage



1

Courage under Pressure

Our family loved sports, especially cheering for our son Matt's basketball team. It was all guts and glory until the day Matt made a life-altering dive for a loose ball and broke his neck. But from that first day, we clearly saw the hand of God at work. As Sharon wept beside our son's body strapped to the hospital stretcher, Matt looked into his mother's eyes and said, "Mom, pull yourself together. Remember, God is in control!"

We prayed for healing, but God chose to show His glory through human weakness. Withholding one miracle became an opportunity for performing many miracles! Today Matt is a quadriplegic, but he navigates his power wheelchair, drives his adapted van, plays video games, and has never suffered from depression.

I'm so proud of my son. If our goal as believers is to communicate the gospel message of faith, I must admit we have done a far better job with a quadriplegic son than we did when he walked. Matt is walking tall by faith, and God is walking with our family.

DR. A. CHARLES WARE—

FATHER OF MATT AND BIBLE COLLEGE PRESIDENT



HAVE YOU EVER RECEIVED a phone call that rocked your world?

Michael Hoggatt and his wife, Mandy, have. Their daughter Summer, who has intellectual and developmental

disabilities, started bleeding a few days after her fifth birthday. After she underwent three months of testing, ultrasounds, and hospital visits, Michael and Mandy received a shocking call. The doctor told them to bring Summer to the hospital immediately, where a bed was waiting for her on the oncology floor. Following another series of tests, a surgeon confirmed that Summer had stage IV cancer. One of her kidneys would have to be removed the next morning or the cancer could prove fatal. Two years later—after undergoing life-threatening surgery, chemotherapy, radiation, CT scans, blood tests, IVs, and more surgery—Summer was cancer-free. She’s a daily reminder of God’s good gift of life!

Dr. A. Charles Ware also received a world-shaking phone call. He was away from his family on a speaking engagement when he was told that his athlete son, Matt, had been injured. “Your son has suffered a C4 fracture,” said the calm, compassionate voice on the phone. “This means he broke his neck.” Charles’s wife, Sharon, called moments later with news that Matt was being transferred to another hospital, and she would be going with him. After Charles hung up, a rush of emotion rose within him. His legs barely held him up as he fought back the weakness and confusion of being so far from his family when they needed him.

Maybe you can relate to these men’s stories—the shock, the uncertainty, the fear. If so, you’re not alone.

Few things shake a man to the core of his being like hearing that his son or daughter has been diagnosed with a disability or severe illness. 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 such as “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 wonder how a loving God could allow such a circumstance into their lives.

In the face of these realities, special-needs dads require a special kind of courage, which comes from knowing they are not alone. Many men have been raising children with disabilities for some time; they can show you how to climb the steep path ahead. These "travel guides" are able to point out where the loose rocks wait and help struggling fathers tie another knot at the end of their frayed rope. Even more important, God is climbing alongside you, continually working His good purposes amid seemingly impossible challenges.

Tempered Steel, Strengthened Lives

When hardships enter our lives, we can be sure that while *we* may be surprised by these things, God is not. He is always preparing us for challenges along the way. Like steel that has been subjected to intense heat until it becomes hard enough to sustain a tremendous amount of pressure and tension, so He has been tempering our spirits to be able to withstand the trials we now face.

Raising a child with a disability can be stressful on an average day. Then there are days when nothing works right, and we're bent under the weight of the situation. On those days in particular, we need to know that God is the Master Operator of our lives. He knows the right degree of heat

required to temper our spirits, preparing us to be able to handle the pressure. God wants to lovingly mold us through life's high-temperature demands.

Are you leaning on God as your Father when pressures rise? If so, you'll experience the joy and peace of relying on Him and find yourself able to stand up under the weight of the struggle. As the writer of Hebrews puts it, "No discipline is enjoyable while it is happening—it's painful! But afterward there will be a peaceful harvest of right living for those who are trained in this way" (12:11).

Softened Hearts, Strengthened Spirits

When we face challenging times, it's easy to think, *This just isn't fair!* We too easily buy into the lie that Christians shouldn't have to go through hurtful struggles. If God is really in control, we would escape pain and suffering, right? No, God wants to teach us that difficult times can also be good. It is through pain and suffering that we can truly come to know Christ.

Paul reminds us that knowing God must be our highest priority. In Philippians 3:10-11 he says, "I want to know Christ and experience the mighty power that raised him from the dead. I want to suffer with him, sharing in his death, so that one way or another I will experience the resurrection from the dead!"

Such a declaration can only be made by a man of courage—one who has been tempered by life's hot spots and shaped under the gentle hand of a Father who watched His own Son suffer. Courage to share in our children's sufferings is not natural—it is a gift from God. It comes from walking closely with *Jehovah-Rapha*, the God who gives comfort in

pain and sickness—who “heals the brokenhearted and bandages their wounds” (Psalm 147:3).

Whatever the specifics of your journey, you can be assured that God wants to build your character and strengthen your spirit through your role as a parent. His purpose is to soften your heart toward your family, your friends, and everyone you meet along the way.

God uses our children, with or without disabilities, to break down our hard attitudes and transform us into men of love and compassion. He uses the emotional (and sometimes physical) suffering that we experience to conform us into the image of His Son, Jesus Christ.

Why Me? Why *Not* Me?

Most would agree that hard times in moderate doses can be a good tonic for the soul. However, the suffering of our precious children is a different story! That kind of stuff can make strong men weak in the knees. Believers and nonbelievers alike are ready to cry out to God for mercy when their child’s welfare is in danger. And when help doesn’t arrive, we want to know why. The key is hidden in the questions we ask when we suffer.

“Why do I have to go through this?”

“Will I ever be happy again?”

“How can this possibly work together for good?”

The questions are focused on ourselves, not on God’s plan.

After more than forty-five years as a quadriplegic, author and speaker Joni Eareckson Tada believes that suffering has a way of deflating self:

Suffering is an important part of Christian living that we all should know more about. Just keep the heat

down to a manageable level, we think. We come unglued, however, if suffering has us at the end of our rope. But that's not a bad place to be. At that point we are forced to think about a greater suffering and turn to Christ on the cross. Don't ponder "me" if you're hurting today . . . ponder the Messiah.¹

Easier said than done! When you've just heard distressing news from your child's doctor, teacher, or counselor, your thoughts don't automatically jump to verses like "Do not be anxious about anything" (Philippians 4:6, NIV). So how do we adjust our focus off of ourselves and onto our Lord?

Adjusting Your Focus

Steve Bundy shares a pivotal "pondering the Messiah" moment that transformed his life and profoundly altered his relationship with his son, Caleb.

One night, Steve was emotionally and physically spent. He was tired of asking God questions about his son's developmental disabilities and getting no answers. At that time, he couldn't yet accept Caleb for who he was—he needed him to be healed. Steve experienced grief and depression over Caleb's condition and felt that his prayers fell silent at heaven's doors. God seemed impotent as his world crumbled. He labored to interpret Scripture out of his experience instead of allowing Scripture to interpret his real-life experience.

At the time, Steve's church support group included friends who believed that healing was for all—no exceptions! So sickness, disabilities, and ailments all resulted from a lack of faith. This group constantly prayed that Steve's faith would increase, his sins would be confessed, and Caleb would be

healed. When he was not healed, they concluded that God's favor didn't rest on Steve or his family.

Steve later discovered that this false teaching focused on man's efforts and was based solely on one's perfection of faith rather than on the Word of God. But in his confusion, he was in a dangerous downward spiral and needed a new, God-centered perspective. One night that perspective broke in on him in a way he could not have predicted.

Many children with special needs have irregular sleeping patterns, and Caleb was no exception. One night when Caleb was two, he awoke crying, and Steve went to his room as usual to comfort him until he went back to sleep. As Caleb dozed off, Steve lay down on the floor and asked God why he had not *fixed* Caleb.

All the therapies and the doctors' visits, all the special time and attention aren't going to help Caleb's development, Steve told the Lord. They won't fix him! Think of all the glory You would receive, Lord. The testimony of his miraculous healing would reveal Your glory to so many!

What happened next shook Steve to the core. He shares his story:

I am not one who would claim to have had many burning-bush experiences with the Lord. But at that moment, I sensed the presence of God filling Caleb's room so strongly that I cannot fully explain it in words. While I did not hear an audible voice, as clearly as I have ever heard anything, I heard these words flooding my soul: *Son, aren't you glad that I didn't require you to be fixed before I accepted you?*

I couldn't move. I couldn't speak. I could only reflect on the words that pierced my heart and mind.

In a watershed moment that I can only describe as a revelation, an understanding of the unconditional love of my heavenly Father burst into my soul.

There I was praying for Caleb's brokenness to be fixed, and instead, I came to grips with *my own brokenness*. Suddenly it became clear to me that God, the, the Incarnate Word made flesh, the Spirit who moves within man, loved *me* unreservedly, regardless of my own performance, abilities, or perceived holiness. God accepted me not because of my worth or goodness. It is because of *His* love and goodness that I can cry out with confidence, "Abba, Father . . . Daddy!"²

In the same way, what flooded my soul that night was how utterly selfish, earthly, and unloving I had been to my own son, upon whom I had placed such high requirements.

Dad, aren't you glad that God didn't require you to be fixed before He accepted you?

With tears running down my cheeks, I held my sleeping son in my arms and said, "Caleb, I love you just the way you are, for who you are, and I don't need you to be fixed. You are my son, and I'll love you unconditionally from this day forth, whether or not you are ever healed."

That moment changed my life. Despite my failures, I have been able to accept my son and rely upon God to form me into the father I'd always hoped to be. That night, for the first time, I realized that it wasn't Caleb who needed to be healed—it was me.

Now, many years later, Steve is amazed that he was blind to God's gift of his son. To be sure, Steve can't ignore the real disappointments and challenges that daily accompany life with disability. His family has experienced a great deal of discomfort and suffering throughout this journey, and as Caleb is becoming a teenager, the challenges continue to increase. As much as Steve loves his son for *who* he is, he does not always love the *way* he is. At the same time, Steve says, Caleb "is amazing and continues to be my greatest teacher. Without a spoken word, Caleb touches more hearts for Christ than a lot of Christians I've known."³

The Truth about Healing

Even if we recognize that God can use pain and suffering to soften our hearts, strengthen our spirits, and adjust our focus, when it comes to our children we still long for them to be healed—to not have to experience the challenges of life with a disability.

Like many believers, we can fall into the trap of focusing our attention exclusively on *physical* healing. Often, we can't comprehend how God might be glorified when a person is not healed physically. But the miracle of healing is that it is first and foremost *spiritual* in nature.⁴

The New Testament uses several Greek words for both physical and spiritual healing: *sozo*, *hugies*, *iaomai*, and *therapeuo*. For example, when Jesus spoke to the woman with the issue of blood, he said, "Daughter, take courage; your faith has made you well [*sozo*]" (Matthew 9:22, NASB). In the next chapter, Jesus commissioned the twelve disciples for ministry and gave them the mandate to "heal [*therapeuo*] the sick" (10:8). These examples are instances of physical healing, where a condition is completely cured.

But healing is also for the soul, as we find in Ephesians 2:8 (NASB): “By grace you have been saved [*sozo*].” Spiritual healing includes a right relationship with God. When a cure was the means to accomplish this restoration, Jesus did so. Otherwise, his ministry was to the heart and soul of mankind.⁵

It is natural to become disillusioned and tempted to abandon all hope when your family is affected by the evil of pain and suffering. Even though we may never fully understand the complexity of God’s natural order, man is capable of experiencing God’s goodness in the direst of circumstances. It is part of the mystery of the Christian faith—a mystery as old as Creation and as fresh as an alert on your smartphone.

Recognizing the Real Enemy

Satan employs an arsenal of weapons to attempt to discourage, defeat, and destroy. Fathers of kids and adult children with cerebral palsy, muscular dystrophy, spina bifida, and brain and spinal cord injuries must keep a vigilant watch to recognize the true enemy. The enemy is not the medical profession, not a bunch of random DNA cells, not the driver who caused the crash, and definitely not *you*! The enemy is Satan!

Some men fail to see this and live defeated lives. Others eventually come to accept this truth and learn to cope with the thousands of details of raising a child with a disability.

It helps to realize that Satan’s abilities are also limited. That’s right! Our enemy has disabilities! He is not free to do whatever he wishes. If he were, the world would be in far worse shape than it is now. God controls evil because He is good.

It took some difficult years of living with paralysis for Joni Eareckson Tada to put the topic of evil in its proper place in her life. “Evil can raise its ugly head only when

God deliberately backs away for a specific and intentional reason—a reason that is wise and good, even if hidden from this present life,” Joni says. “God permits what He hates in order to achieve what He loves—it’s just that most of us won’t see it until the other side of eternity.”⁶

Your Story Isn’t Finished

Fortunately, God sometimes affords us glimpses of eternity in this life. Along the way, He reminds us that He can bring good out of any situation—including yours. He sees every moment you put into the care of your child and family. He sees the private tears, feels the hidden pain, and hears the recurring questions. He sees the love, the compassion, and the service you and your family give to one another. Isn’t it reassuring that these things “count” with God? Regardless of what you’ve had to sacrifice to care for your son or daughter with a disability, your ability to love God and people has not diminished a single bit. If anything, you’re probably more aware of opportunities to serve others than you ever were before.

When God has you in the refining fire, it’s natural to cry out and beg Him to turn down the heat. But remember what’s on the other side of that experience: a deeper, richer, more compassionate heart—the heart of our heavenly Father abiding in us.

Traveling Tips for Dads

When the pressure comes on strong . . .

Don’t Walk Away!

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.

Action Step: I will decide on several ways to spend quality time with my family, and then follow through.

Don't Lose Your Focus!

Emotional and physical challenges that accompany disabilities can sometimes be traumatic for the whole family. When dealing with a stressful situation, some dads count to ten, but it also helps to stop and picture Jesus standing beside you. Remember, He is the One who took on human form and is able to relate to whatever pressures you might face.

Action Step: I will choose a Bible verse from this book's chapter, write it on a note card, and focus on its truth this week.

Don't Forget to Laugh!

Laughter is like a refreshing stream encountered while walking along life's dusty trail. It gives us a moment to rest and refocus on life's God-given treasures.

Action Step: I will look for humor in the everyday and share those moments with my family.