JAMIE SUMNER

eat, sleep, save *the* WORLD

Words *of* Encouragement *for the* Special Needs Parent

B&H
PUBLISHING
NASHVILLE, TENNESSEE

Printed in the United States of America

978-1-5359-7109-6

Published by B&H Publishing Group
Nashville, Tennessee

Dewey Decimal Classification: 649.8
Subject Heading: PARENTING / DISABILITIES / PARENTS OF HANDICAPPED CHILDREN

Cover design by Tim Green, FaceOut Studio. Imagery © Amy Covington/stocksy and Hong Vo/shutterstock.
Author photo © Bethany Rogers.

1 2 3 4 5 6 7 • 24 23 22 21 20

For Gigi
words are not enough

Acknowledgments

Typically, acknowledgments are filled with the people who make a book possible. But I can't do this properly without first acknowledging the people who make my *life* possible:

Charlie, I wouldn't have dared write a word of this without you. You made me a mother and taught me how to let go of my agenda for life. You brought me closer to the person God intended me to be. I am so proud of all you have accomplished and can't wait to see what you will do next. It will be remarkable, I am sure.

Cora, Jonas, you two made our family complete. I love your energy, our chaos, and how you care for your brother. The way you love him is how I wish we could all be loved.

Jody, your support of my writing and our family makes it possible for me to tell our story. Without you, there *would* be no story. The last eleven years have been a wonder. Here's to many more.

To all the parents and therapists at High Hopes preschool, thank you for creating such a special place for special kids. And to Jill, Charlie's first SPED teacher as a fully-fledged kindergartner: you are the one I prayed for. Thank you for pushing him to show the world how smart he is.

Lastly, the grandparent force is strong in our household, and I am forever grateful to Jan, Jim, Judi, and Glenn for spoiling my kids.

Now for the people in the book business who brought this story to its fruition:

Keely, you know how much you mean to me. Thank you for being my agent and believing in this book through all the bumps and turns in the road. We've done a lot of good work together, and I can't wait to see what comes next.

Ashley, I didn't know what I'd lucked into at B&H in getting you for my editor. Your knowledge of the Scripture is unparalleled. You are hereby and forever my theology fact-checker. That combined with your heart for kids like mine was a knockout force of editing prowess.

Writing is a solitary act. Parenting often is as well. So I am doubly grateful for my fellow writers whose kids have special needs. Alethea, Jillian, Valli, Calleen, Mia, Brynn: thank you for doing all you do while going about life in disguise as ordinary humans.

Lastly, to the families of children with special needs who read this book: I pray it brings you comfort and solace and joy and peace and strength and whatever else you might need today. I am grateful to know you are in the world and that we can parent together in God's grace.

Contents

Preface. xi

Part 1: Determination

An Introduction 3
Chapter One: Overcoming Guilt. 7
Chapter Two: Overcoming Imperfections 17
Chapter Three: Overcoming the Safety Net. 29

Part 2: Hope

An Introduction 43
Chapter Four: Hope like a Child 47
Chapter Five: Hope like a Prophet 55
Chapter Six: Hope like a Dinner Guest. 67

Part 3: Resilience

An Introduction 79
Chapter Seven: Bouncing Back from Unmet Expectations 83

Chapter Eight: Bouncing Back from the Unforgivable 97

Chapter Nine: Bouncing Back from the Edge 107

Part 4: Patience

An Introduction 121

Chapter Ten: Waiting for Help 125

Chapter Eleven: Waiting for the Anger to Pass 141

Chapter Twelve: Waiting for the World to Catch On 153

Part 5: Laughter

An Introduction 163

Chapter Thirteen: Laughing at the Absurd. 167

Chapter Fourteen: Laughing at the Changing Tides . . . 179

Chapter Fifteen: Laughing at Being Outdone 193

Part 6: Thankfulness

An Introduction 205

Chapter Sixteen: Thankful for What We Have 209

Chapter Seventeen: Thankful for What Was. 219

Chapter Eighteen: Thankful for What Is to Come 231

Notes. 239

Preface

It took more than four hours to disassemble my twins' toddler beds and reassemble them into beds for full-sized humans. It shouldn't have taken this long. What is a series of boards and bolts and screws when up against a woman armed with an Allen wrench? Perhaps, if the directions had not been smudged photocopies of photocopies, I would not have screwed the frame in upside down. If the nuts and bolts did not have to be inserted into tiny, pea-sized holes, it all could have gone smoother. If I had waited for assistance rather than insisting that I do it on my own, perhaps I would not have ended up with bloody knuckles. Then again, maybe not.

If things had gone a thousand different ways, perhaps I would have appreciated the momentous occasion that was the final transition from baby to kid. But instead, my husband, Jody, and I finished the last touches on the beds, literally ripping the plastic off the mattresses, one hour *past* bedtime. The kids were weird and wired in that way that kids get when they wander into uncharted hours. They jumped excitedly, literally bouncing off the walls at 9:00 p.m. And me? I sat on the floor and considered my options:

Cry? Sleep? Take a picture so I could look back more fondly on this moment than I was just then?

This is how it always is with me in the big moments, especially with Charlie, their older brother, who has cerebral palsy.

Whenever he crosses a developmental rung on the ladder, I am caught wrong-footed. I am so worried about the twins wandering off at the park that I miss his unassisted sitting until he topples over. I am struggling with my phone, trying to get it to record, when he takes that first step in the gait-trainer. I am holding him in my arms and talking to one of his aides at school and do not notice that he is signing for “more, more” kisses, and so I feel bereft when I finally see it and he’s moved on to wanting more of something else. I miss the magic of the moment.

When he finally learned to chew properly, it wasn’t me who taught him. It was his feeding therapist in his preschool classroom to the applause of all his peers. “Chew, chew, chew!” they cheered, and he did. When he finally stopped using his speaking device as a really fun iPad and actually began to communicate with it, he was also at school. According to his speech therapist, he introduced himself to a group of touring parents. Unprompted, he typed out, “Hi, my name is Charlie. This is my speaking device.” Of course he did.

If I’m not careful, the guilt can build quickly, like rain that swells a river and finally breaks the dam. There are so many options at hand for this kind of self-recrimination. Parents are great at this. Parents to children with special needs are perhaps the best at it. Because we have to do more for our children, we feel it acutely when we let them down. When we fail to properly celebrate the milestones or simply don't engage as much as we could, we feel it like a hunger pang.

And yet, if I zoom in on a different still-shot of this life we are living, I see all that I *am* doing. I *did* put those beds together like Wonder Woman with sheer force of will and a teeny tiny wrench. I *did* fight the insurance company for that speaking device, and I *did* catch the next ten steps in the gait trainer and the criss-cross applesauce sitting in the park. I continue to chant "chew chew chew" at home. And I give the hugs and the smiles even when I'm bone-weary, even when it is an hour past bedtime, even when the days run together and I forget to take that picture of the first night in the "big kid" bed.

When I look at it from this angle and in this light, I begin to see the magic and let the guilt go. This is what *Eat, Sleep, Save the World* is all about. It is about learning to flip your perspective so you can see what you *are* doing right. In the six sections that follow, I hope you can begin to see that God has gifted you with the determination, hope, resilience, patience, laughter, and thankfulness you need to excel in this parenting game. This book is meant to be a source of encouragement and camaraderie and spiritual support so you remember that with God's help, you *are* a superhero to your child.

PART 1

Determination

An Introduction

Determination

noun

firmness of purpose; resoluteness

synonyms

willpower, strength, decidedness, steadfastness, boldness, courage, persistence

i.e., What you already have by the handful, even when you feel like giving up. Because you never do. You never give up. By God's grace you rest and then walk on.

Grit. This is the word that sticks with me, sticks in my teeth like a coffee ground, when I think of the great heroes from the old comics. There are heroes that are just so-so, in my opinion, ones I could take or leave, perhaps because they seem to have it easier than others. Superman, for instance. He's a little too glossy for me. I know he's not from these parts and there's a necessary orienting process that comes with travel, but he's a little too pretty, like Prince Charming from *Shrek*. I grew up on the Christopher Reeve *Superman*, and no other actor before or after could ever suffice. Remember that curl of hair that fell just so in the center of his forehead, like a Kewpie Doll? Beautiful, yes. But he wasn't exactly gritty standing there in his spandex, flexing his freshly shaved jaw. The real Christopher Reeve, however, he had grit. Put him on a horse and he took up residence in that special pocket of my heart reserved for Clint Eastwood and Robert Redford, maybe Brad Pitt, à la *Legends of the Fall*. Then, in 1995, Reeve fell from his horse, becoming a quadriplegic.

Here's the grit part. On a ventilator, in a wheelchair, he lived out the remaining nine years of his life lobbying for others who suffered from spinal cord injuries and trying to get people to come around to the idea of stem cell research before it was really understood and long before it had any crowd appeal. I'm not sure how I would have fared, having once had all the use of my limbs and then not. It's a before and after that only by the grace of God I would have handled with such . . . grace. If left to my own devices, I'm fairly certain I would retire to the couch with a drink and Sylvia Plath's collected works.

In the 1978 *Superman*, Jor-El says this to his son:

> "You will travel far, my little Kal-El. But we will never leave you . . . even in the face of

> our death. This richness of our lives shall be yours. All that I have, all that I've learned, everything I feel . . . all this, and more, I bequeath you, my son."[1]

Isn't that what we all want to say to our kids—that we will never leave? But we will have to let go a little now and then more and more. Parenting a child who needs help to move, to speak, to interact with others is gritty. It takes courage and determination to know when to help and when to let go, when to fight for them and when to let them into the ring alone. This world moves at a brisk pace and does not hold out a hand for the stragglers.

But your children *can* keep up. You know this. It's why you keep going, even when you feel it the least, especially then, because that is when God steps in to nudge you forward. This is what keeps you digging the wheelchair out of the muck and stretching legs and teaching sign language and assuaging fears and wiping tears and running toward, not away, from new situations. Their successes, both tiny and huge, keep you going. No, you are not going to get it right all of the time. But God doesn't require that. He wants you to believe that you can help your children succeed by relying on Him for that strength. He is the only one who can keep you from being world-weary. Being a hero for your kid is messy and full of the ups and downs of ordinary life . . . and then some. But God will give *you* the push so that you can give *them* the push they need to keep rolling under their own steam, which is what true heroism is all about.

Christopher Reeve would have always been a good Superman. He had the talent and the wingspan and the dimpled chin. But he was a better one *after* he hung up the cape. He led by example and through his own weakness, just as God calls us to do. Reflecting on his life in his book, *Still Me*, Reeve said, "I think a hero is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles."[2] I can't think of a better mantra for us, as parents of children with special needs, but also as Christians. Grit, not perfection.

CHAPTER ONE

Overcoming Guilt

I know you've heard the phrase "mom guilt." It's a cliché that weighs heavy on the shoulders of thousands of women as they go about their days feeding, dressing, loving, disciplining, and educating their children. It's societal, yes, but even more so it's a weight we as parents tie around our *own* necks, a perception of our misdeeds—that harsh word we said at the park, the rushed bedtime because we can't do another minute of the day. We see our own "failures" and put our self-worth in time-out.

Mom guilt is exhausting. It's not a way to parent, or live.

But there's something extra that only applies to some of us, a dose of guilt more concentrated that only a certain percentage of the population can understand. It's a load that burdens men and women of all shapes and ages; I call it "special-needs guilt." It's another several thousand pounds on the barbell that can make your heart shake for the gravity of it if you let it. It takes all other parenting woes and raises the ante—by a lot. Every parent of a child with special needs carries a list in their heads of what needs to be done, who needs to be called, what goals need to be pushed for, and which ones to lay aside. And only we know when corners are cut: when we don't stretch little limbs for the minimum count, when we don't use the expensive stander/gait trainer/speaking device as often as we should, when we skip the birthday party because the sensory stimulus is too much for *us*, when we turn on the YouTube video instead of engaging at the end of the day.

When you have a child who does not skip along the milestones, the responsibility falls on you to help direct them down the path, and when you stop to rest, it can feel as though you're hitting the pause button on their progress. And even though you know that thought is probably ridiculous, the thought alone is too much pressure. We can't do everything. We aren't God, after all. Which, of course, is the point and the only belief that will give relief. We aren't God and so we're going to falter, and we're going to need rest, and we're going to let our kids down, like any other human. The guilt will come, of course, but it doesn't have to last. It doesn't have to be the drumbeat of your heart. If you can shed this feeling, like an unnecessary layer of clothes, it can be your greatest strength and freedom.

When my son Charlie was still in utero and the size of a spaghetti squash, he was diagnosed with Beckwith-Wiedemann syndrome, a rare genetic disorder that took me years to learn to spell. We call it "BWS," because who has time for seven syllables? Most people have never heard of BWS. It sounds like a law firm. In reality, it is a disorder that results from the imprinting centers on chromosome 11 refusing to regulate a few tiny bits of DNA that control growth. Somebody forgot to hit the stop button on the pituitary glands. As a result, Charlie would be big. Bigger than most. His tongue, which had been so entertaining to spot on the ultrasound at twenty-two weeks, was also the first clue to his condition. It would be enlarged beyond what you can imagine and so I will not make you try. Other risks: his kidney and liver could also be bigger, as could one side of his body. And certain cancers and tumors flourish in BWS kids—like mold on bread, they provide the perfect environment to incubate. But supposedly, around age eight, the pituitary gland starts to do its job. Most adults with BWS are normal-sized. We just had to make it past the tongue and the potential cancers and general giantness first. If you can get beyond the scary stuff, it's mostly just weird.

This diagnosis was my first taste of special-needs guilt—and he was still in utero. If I traced the lines of events back to the beginning, it very much looked and felt like it was all my fault. You see, due to infertility, my husband, Jody, and I had sought medical intervention to get pregnant. Charlie was a product of IVF. So how could I not ask myself over and over if his syndrome was a result of our method of conception? Was it the science and our desperation that made him how he is today? Could it be that our greed for a child led to a syndrome that led to a life that could have been better if we had left well-enough alone? All my research and that of our reproductive endocrinologist and geneticist proved indeterminate. No one knows why BWS happens. But all the rational thought in the world wouldn't help me now. With no other place to point a finger, I pointed it at myself. It was my fault that Charlie would suffer.

My guilt had a limited time to ripen, however, because at thirty weeks, when Charlie was the size of a decent cabbage, I went into labor. Ready or not, I was going to meet my son. Only then would we find out the rest of the story—the elaboration and extension of his diagnosis, which would follow us much longer than his first eight years.

Having been pulled from various pursuits in fishing and taxes, the disciples were forever in the midst of job-training as they tracked Jesus throughout His ministry. It was one long orientation for what would come after the Ascension when they would be left to their own devices. Like any good Socratic student, they leapt at the opportunity to ask questions. At one point, in the ninth chapter of the book of John, Jesus walked His followers past a blind man. Unlike someone struck blind by a degenerative disease or injury, this man had been blind from birth. He'd never seen an olive, could not describe the color green. And there was no attributable cause for his ailment. This led the disciples to ask, "Rabbi, who sinned, this man or his parents, that he was born blind?" (John 9:2). Good question.

Let us pause here for a moment. Jody and I *know* that our sins did not cause our child's disabilities. We would fight anyone who would suggest such a thing. And yet we have all read about or heard from a friend—or maybe even experienced ourselves—an instance where the parents are blamed for an absolutely unpreventable diagnosis. Autism? "You must have gotten your child immunized." Down syndrome? "You waited too long to start a family. Odds increase with age." Someone, somewhere, always has something to say. These statements, when you read them, seem ridiculous. No one would buy that. These people need to get off the Internet. But if I'm honest, I catch myself following this train of thought when it comes to my own parenting. I want to trace every hard thing back to me. And I lived in this low valley of guilt for years after Charlie was born, especially after he received his second and more long-lasting diagnosis.

Charlie was delivered into a room full of specialists. At the recommendation of our maternal fetal specialist, we went straight to the university hospital rather than the standard hospital that we had toured. We needed the experts. And so, at six o'clock in the morning, they stood ready . . . neonatal doctors, respiratory therapists, geneticists. This would be the team that would intubate and rush my child away into what we assumed was the safety of the NICU. And at first, all appeared to go according to plan. His tongue was huge. But it was also comical and adorable in its own way. With his tiny body and that tongue sticking out, he could have been an imp, an elf on a shelf. And because he was intubated, his breathing was stable, albeit artificially, for the moment. Everyone assumed he would grow into the tongue if given time.

But we did not get time. A month into our NICU stay, I entered Charlie's tiny box of a room with freshly sanitized hands holding a cooler full of pumped milk, ready to take his temperature, change his tiny diaper, and hold the nasal feeding tube while he "ate." I was trying to be a mother in all the ways they would let me. But that day, I wouldn't get to do even that. That was the day they told me that the head of the NICU would like to speak with me.

Nothing good happens when the head of the department requests a meeting. I did not know that at the time. When he came in after rounds bearing a file folder of papers, the "Charlie chart," I shook his hand, still ignorant of the purpose of his visit. The first tingle of fear crept in when he asked, "Is your husband with you?" I said no and then refused to call him, not wanting to pause, even for a moment, this train heading straight for us. I felt it—the still, dead air before the lightning strike. The doctor pulled out a black-and-white photo of Charlie's brain. There were white spots on gray, like paint splatters. Except these splatters were absences of healthy tissue, black holes in the atmosphere. "Periventricular Leukomalacia," the doctor explained. Eleven more syllables to add to the list of unmentionables. PVL. Damage across all four quadrants of his brain. Almost certainly cerebral palsy, although they would not dare make that particular diagnosis before age one . . . because no one "had a crystal ball," as the medical professionals like to say.

It was the end of one way of life, one that had a start and stop date to its abnormality (eight years), and the beginning of another, one without an expiration.

What would his life be like?
Would he walk, talk, breathe on his own?
Would he have a life he could love?

These were the questions that came first. The ones that came later, in the darkness of sleepless nights, were more insidious and even more impossible to answer.

What caused the brain damage?
When did it happen?
Was it my fault?
How did he get so hurt without my knowing?

The doctors never pinpointed a direct cause. There was no particular trauma at birth or in the NICU. It was unexplainable, but my psyche liked to fill in the blanks. There was that one time during pregnancy when I got a small shock from plugging in the computer cart at the high school where I taught English. Once I slipped on the stairs and sat down hard. I unknowingly ate unpasteurized cheese at a restaurant. The list was endless and ripe with anxiety. It took years and hours of prayer and small, kind words from others for me to let loose this particular bundle of guilt. And sometimes, if we've had a particularly bad day, I still find the string and tug it along with me like a deflated balloon.

* * *

When Jesus answers His disciples' question as to who they should blame for the man's blindness, He responds definitively and without pause. He says, "Neither this man nor his parents sinned. . . . This came about so that God's works might be displayed in him" (John 9:3). We do not know if the parents were nearby or even still living. We do not know if they received this blessing of release from the Son of God. But we do know what comes after.

Jesus spits on the ground and rubs the mud made from His own saliva onto the man's eyes. After rinsing away the mud in the Pool of Siloam, the blind man sees for the first time in his life. And when Jesus says the works will be "displayed," they are for all to witness. This man is going to be questioned by friends and neighbors and any passersby who knew him only as "the blind man." They're going to want to know if his green looks like their green and who is responsible for such a miracle. And he will answer, without compunction: "The man called Jesus made mud, spread it on my eyes, and told me, 'Go to Siloam and wash.' So when I went and washed I received my sight" (John 9:11). If all things work together for good, then ailments and remedies serve the same purpose. Sickness and health, wealth and poverty, all of it can lead to the same glorification of God if we stop trying to point the finger at ourselves. That is the hardest truth to hear when you are not parenting the miraculous recovery, but instead in the thick of it with a child who might not see healing until heaven. But it is the *most* necessary truth and the only one that can absolve us from that cycle of blame.

This is what I could not understand when Charlie first received his diagnoses, his blanket statements of BWS and PVL that would wrap themselves around all of us whether we wanted them or not: *there was no room for guilt in this space.* Jesus did not create humans to wander aimlessly through the what-ifs. He created us to live a forward-looking life free of any rumination that does not lead to thankfulness. The guilt of the special-needs parent comes in many forms, but it all comes from the same source—ourselves. And if we can turn our eyes toward the Jesus who has a purpose for a different-looking life, then our lives can be good. Our different can be good. Our different can be a testament not just to *triumphing* over hardship, which is what we hear all the time from those who cannot fathom our situation, but to *embracing* the hardship. It has made our children special in all the good ways. We are set apart and there need be no guilt or shame in that.

I needed to understand that God didn't want me to live in the land of what-ifs. He wanted me to trust Him with Charlie and believe that in His strength, I could do that. If you're anything like me, then you need to hear that God wants you to believe the same. He wants you to see that you can trust Him to take care of the past, present, and future, for your family and your own trembling heart as you try to parent as best you can. So know that. Embrace it. Stop the condemnation. And walk in the power of knowing that you aren’t blamed, you are *chosen*. You aren’t punished, you are *set apart.* Live in that power.

Reflection Questions

As you read John 9:1–12 and reflect on this chapter, answer the questions below:

1. When have you felt the guilt that comes with parenting a child with special needs?
2. How do your child’s differences bring blessings into your life?
3. How might you grant yourself grace in the middle of a guilt moment?
4. Who in your life needs to hear how God frees us from guilt, both in parenting and in every other way?