

“Joy often feels like a fickle and elusive friend to parents overwhelmed by the challenges of raising a child with special needs. In *Get Your Joy Back*, Laurie Wallin takes parents like you and me by the hand. In the telling of her story, we learn that she once lost her joy and then, by the grace of God, found it again. Then she gently guides us back to the joy waiting to be found and embraced when we choose forgiveness and gratitude instead of blame and bitterness. If you need to get your joy back—and what parent of a child with special needs doesn’t at some point in life?—Laurie Wallin’s encouraging book is the place to make it happen.”

—Jolene Philo, author of *Different Dream Parenting*

“When I fly with my boys, the flight attendant stops by our row and reminds me that if there’s an emergency, I’m supposed to put on my oxygen mask before I help the boys put on theirs. Laurie’s words remind me of that principle—if I’m not taking care of myself, I can’t take care of anyone else. Writing honestly about her own struggles and successes, Laurie guides readers through areas of unforgiveness that, if left unchecked, can become areas of bitterness. She will be your biggest cheerleader as she helps you examine your heart and release what’s holding you back from experiencing joy.”

—Sandra Peoples, coauthor of *Held: Learning to Live in God’s Grip*

“As a special needs parent I have lived in that isolated, lonely, and broken place for many years. Laurie bravely pulls back the curtain on the struggles and emotions that come with having a special needs child. But she doesn’t stop there. She grabs you by the hand and walks with you from that broken place to a place where you can live life with joy and contentment. A place where you can enjoy motherhood and your children.”

—LaToya Edwards, author of *Beautifully Broken*

“The world needs this book. I need this book. *Get Your Joy Back* is a communion from which all special needs parents should partake. Read it and expect to be validated, encouraged, challenged, and spurred on.”

—Gillian Marchenko, author of *Sun Shine Down: A Memoir*

“Laurie writes while in the trenches—her words mixed with humor and reality will resonate with parents as we battle resentment and fight for joy in the world of special needs. This book will ask you to shift your gaze by the power of forgiveness and lead you to cultivate joy in the deep parts of your heart and in every relationship. By the end, you will realize you’re no longer staring at a dark wall but have a choice to enter a grace-filled place with breathtaking possibility, hope, and joy.”

—Kara Dedert, blogger at karadedert.com

Get Your Joy Back

Banishing Resentment and Reclaiming Confidence in
Your Special Needs Family


LAURIE WALLIN


 **Kregel**
Publications

*Get Your Joy Back: Banishing Resentment and Reclaiming
Confidence in Your Special Needs Family*
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Published by Kregel Publications, a division of Kregel, Inc., 2450 Oak Industrial
Dr. NE, Grand Rapids, MI 49505.

Published in association with the literary agency of Credo Communications,
LLC, Grand Rapids, Michigan, www.Credocommunications.net.

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ISBN 978-0-8254-4339-8

Printed in the United States of America

15 16 17 18 19 / 5 4 3 2 1



*To my mom, Beverly,
who prayed me through this project.
And to my husband and daughters,
for courageously permitting me to share our story.*



CONTENTS

<i>Foreword by Joni Eareckson Tada</i>	9
<i>Invitation: Come in from the Cold</i>	11
1 Yes, You <i>Can</i> Enjoy Life Again	15
2 Looking in the Mirror (Forgiving Yourself)	23
3 Restoring Joy in How You See Yourself	33
4 When Special Needs Don't Feel Special (Forgiving Your Child)	41
5 Rediscovering Joy with Your Special Child	51
6 For Better or for Worse (Forgiving Your Spouse)	59
7 Rekindling Joy with Your Spouse	73
8 Can't We All Just Get Along? (Forgiving Extended Family)	83
9 Regaining Joy in Your Family	91
10 When the Pros Don't Know (Forgiving the Professionals)	99
11 Reclaiming Joy and Confidence with the Pros	111
12 Life on the Sidelines (Forgiving Church and Community)	121
13 Rebuilding Joy in Community	133
14 Is God Even Listening? ("Forgiving" God)	145
15 Rediscovering Joy with God	155
 <i>Author's Note</i>	 165
<i>Notes</i>	167
<i>About the Author</i>	175

Foreword

Bob and Stephanie sat in the parking lot, watching as people entered the church for Sunday services. Julie, their teenage daughter, sat in the back seat with Jason, their 10-year-old son with autism. “Why are we just sitting here?” Julie fumed. “Why aren’t we going in?”

Stephanie glanced at her husband, wondering the same thing. Bob’s jaw was taut and his eyes were damp. Right then Jason began his usual rocking back and forth and hitting his legs. “Help your brother!” Bob barked at Julie. As she grabbed Jason’s arm, Stephanie reached for her husband’s hand and whispered, “If you want to skip this, we can.”

The family was new to this church. Bob had explained to the pastor that Jason had autism and would need assistance in the children’s class. The first few Sundays had passed without any disruption, but last week was different. The children’s class became noisy, which created “sensory overload” for Jason—he went ballistic, frightening his classmates and alarming his teacher.

Bob and Stephanie were told that Jason could not attend Sunday school anymore without adult supervision. They left church that day feeling guilty and embarrassed.

Bob broke the silence. “So which one of us should sit out here with Jason? You or me?” he asked, glancing at Stephanie. They could hear the service getting started with singing. Bob looked at his watch. “Maybe we’ll come back next week,” he abruptly announced and started the engine.

“Aw, man,” Julie whined. “I was just beginning to make friends here.” The family drove away in stony silence.

The story is true. And it’s repeated countless times every day—maybe not in a church parking lot, but in restaurants, shopping malls,

and supermarkets everywhere. Mothers and fathers of kids with special needs are in desperate need of help. And the fact that you are reading this book indicates that you are probably one of those mothers or fathers. You've poured out your heart in support groups, you've gone on websites to gather info on your child's disability, but still, your energy is sapped and your joy is drained.

You love your child. You'd give anything to lighten his or her load; still, you find yourself looking back on your wedding day, wondering if you'd have said your vow had you known what you were getting into. Disability can test the best of marriages. And if you're a single parent raising a child with special needs? It's doubly hard.

This is why I give a hearty thumbs-up for Laurie Wallin and the insights she shares in *Get Your Joy Back: Banishing Resentment and Reclaiming Confidence in Your Special Needs Family*. Laurie understands the pitfalls (but also the incredible joys) of keeping your family's sanity when disability is in the mix. She speaks from great experience, so I encourage you to turn each page slowly—savor the insights and write down the suggestions; use a yellow highlighter and reflect often on the illustrations. Start a journal and write down personal and family goals. Gain as much wisdom as you can and know that you are not . . . alone.

You are part of a growing movement of parents of children with disabilities who are heaven-bent on trusting God in all the hard places of your family's life. You are among those who understand that, yes, life is supposed to be difficult—but it opens the way for God to pour out grace upon grace into your weakness. Most of all, you are among that remarkable echelon of parents who cling tenaciously to hope. Just like my friends Bob and Stephanie who, by the way, are beginning to make big strides forward in their family.

So be encouraged, friend. Help is on the way—and it begins as you start turning the pages of *Get Your Joy Back*.

Joni Eareckson Tada

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Invitation

COME IN FROM THE COLD

“Hold on a second,” I tell my friend on the phone. “I can barely hear you. Let me see if I can get a better signal.” I walk to the next room in my house. The kids are all in there, drawing, playing games—doing the kinds of things that will inevitably pull me from my phone call within the next three minutes—when two of the four girls start arguing over whose marker is whose.

“Okay, I hear you now,” I say. But as she talks, I hear her voice in broken fragments. So I move again. “Hang on, let me try another room,” I say loudly, as though my volume change will overcome the lack of connection. In the back of my mind, the timer is ticking—the one that keeps me vigilant with my daughter who has enuresis and encopresis (chronic wetting and soiling conditions). *How long since she’s gone to the bathroom?* I wonder, then dismiss the thought as I walk and check with my friend: “Can you hear me now?”

No dice.

I walk outside my house, stand on the driveway, and try again. “What about now?”

Nope.

I keep walking and checking in with her, until I find the perfect signal. Crystal clear, I hear her talking about a situation at work, about her family, and how she’s doing. We talk for about twenty minutes and say our good-byes. I’m in shock as I realize I snuck in a whole conversation without . . .

The screaming.

How long has that been going on? I groan.

I begin to stand up and realize I've been sitting on the concrete in the corner of my driveway, feet in the street. Muscles stiff, arm tired from holding the phone in chilly evening air, I stand up and stretch. Half stumbling, I will my body toward the too-common battlefield inside.

How did I not notice I was cold, uncomfortable, and stiff until now?

Because that's what we parents do. We accommodate. We manage situations, life, our kids, their needs, our marriages, and whatever else is happening—most of the time not even knowing how we're doing in the moment or what we might need—until our bodies, minds, or best friends tell us we're a mess. That's the crisis point that reminds us we've been sitting in the cold for God knows how long, trying to get a signal in that situation or relationship.

Welcome to the book that will help stop the madness. A resource that will equip you to stop ignoring yourself and pushing a hundred miles past what you can reasonably give as you care for kids who are extra . . . everything. A little (or a lot of) extra energy, effort, emotion, care, planning, and discipline. While dozens of wonderful, practical books exist for us who raise children with all combinations of special needs, this one is dedicated solely to you and your well-being.

A well-being that includes and extends beyond the physical, emotional, mental, and social realms of existence. That allows you to daily say it is well with your soul in all of the relationships you encounter as a parent, many of which can seem to be more of a stressor than a blessing when you're raising kids who are . . . *special*. Kids outside the bell curve: possibly clinically diagnosed with one or more special needs, or maybe “just” an overflowing handful of strong-willed, toddler-aged, or extra-smart personhood.

If the child you're raising is clinically diagnosed with a special need (or, like ours, a few each), or you suspect they've got one, or your child isn't even technically a child anymore (they're over eighteen) and your friends are off on cruises and you're still walking your grown man-child to therapist appointments, this book is for you.

You, that parent who needs to take care of yourself in the lifelong ministry that is raising your special child. You, the person who serves as a buffer when your child's reality clashes with the school's, their friend's,

their doctor's, or the unsuspecting passerby at the store. You, the person who is more than simply "parent," who has unexplored or underdeveloped gifts and talents God wants you to recognize, use, and enjoy abundantly. You, the one who's been sitting on the far corner of your cold concrete driveway, neglecting yourself for way too long. You, whom God desires to live deep, life-giving joy today—and every day—into eternity.



God desires you to live deep,
life-giving joy today—and
every day—into eternity.



Sound too good to be true? Yeah, I hear that a lot. At a conference I attended recently, a mom of a child with bipolar disorder shared her story, heard mine, hugged me, and pulled back incredulously, asking, "With your family situation, how is it that you're smiling, dressed in matching clothes, and have your hair and makeup done?" Not that looking put together means I'm internally put together, but it does say something: taking care of ourselves isn't the norm as parents raising kids with extra needs. It's the exception. But it's also *possible*—and even graspable—if we get intentional, get realistic, and get rid of what holds us back more than anything else: the stress.

That's what I hope this book will do for you—help you deal with your stress in ways that are intentional, realistic, and that make space for the joy you sorely need. Not happiness-joy, or feelings-joy (though those are good too), but "the joy of the Lord is our strength" kind of joy. Joy that bolsters you against challenges. Joy that replenishes the depleted hopes and dreams. Joy that restores you after those days you think you'll never get through. Joy that whispers "you matter" when you feel invisible, that shouts "God reigns" when you've started to lose hope for that long-awaited treatment. Joy that fills the empty moments and overflows into the lives of others, with extra to spare.

Ready for that kind of joy? Then read on, brave friend!

Laurie

One

YES, YOU CAN ENJOY LIFE AGAIN

“I’m so tired,” she says, looking down at the table, her finger tracing the wood’s grain. “I just don’t know what to do.”

I nod. I know that place too.

“I mean, my daughter’s so intense. I’ve read every book and article that’s supposed to help. I’ve tried everything people recommend. All that work with counselors led us nowhere. The classes, support groups . . . even getting her an IEP . . .” Her voice trails off. She’s looking for something. Words? Feelings? Maybe the magic bullet she’s missed that would make everything just . . . work. Or make any sense whatsoever.

“And you know what? I even tried that crazy idea from the tabloid magazine!” She laughs. But her eyes search mine for judgment.

“See?” I seize her levity. “You’re as nuts as I said you were!”

She laughs again. I smile too. Then tears fall. Fast.

“We’re doing the best we can with our daughter,” she continues. “I just don’t have a clue how I’m going to do this forever! I can’t even relax sitting here at lunch with a friend.”

Tears keep coming. I hold her hand and we sit together. I want to embrace and hold her tight. Make her laugh again. Tell her she’s not alone. But she may as well be on an island at the South Pole right now. Even sitting with someone who understands as I do—even amidst the smiles, the touch, the gallows humor—the isolation she feels is almost palpable.

What about you? How are *you* holding up?

If you're like me, the answer is probably something like, "What do you mean . . . 'me'?" And if that's how you're feeling, I assure you, you are not alone.

I repeat: you are not alone.

There's not much space in a family with special needs kids for us as parents to have a life of our own. Or even consider one. Instead, we manage our longings and stress in odd ways. Maybe you can relate to my experience a few years ago.

With one child diagnosed and beginning medications, hope was rekindled for life without hours-long screaming fits and broken walls. But then, after years of appointments, when our second daughter's moods still raged undeterred, I stuffed the stress deep inside. I ate it away. I cried it away. I took antidepressants. I blogged it away. I overextended-myself-in-service'd it away. I screamed it away. I even punched-a-hole-in-my-bedroom-wall'd it away.

It didn't go away.

All I was left with was a chubby, angry, bitter, overworked me . . . and a hole (or two) to patch in my wall. I looked in the mirror one morning and said, "Lady, you look *old*." At thirty-five!

Turns out there's a reason for that. (Here's where I geek-out on you. I used to be a science teacher.) Aging happens as our DNA, the delicate molecular template for life in all our cells, begins to unravel. We all have special structures called telomeres that cap the ends of our DNA strands, stunting the aging (unraveling) process. Unfortunately, stress causes these protective caps to shrink and wear out. In other words, we are actually aging faster than we would have without the chronic, unrelenting pressures of caregiving.

Great news, right?

In a recent documentary, UCSF researcher Dr. Elizabeth Blackburn reported that the length (and thus protective nature) of telomeres is much shorter for parents in our situation. Stanford University neurobiologist Robert Sapolsky added that for every year of chronological age, special needs moms experienced roughly six years of cellular aging.¹

My friend at lunch that day is not the only tired, stressed-out parent

raising special needs kids. We're all living it. We get up, wash up, make the coffee, and jump in with both feet to intense lives of:

Repetitive, rigorous physical care. We lift, shift, bathe, and assist our kids. In cases like my daughters', who have mood and developmental disabilities, we must even restrain them and physically protect siblings when they act out aggressively.

Hyper-vigilance. We maintain for a lifetime the level of vigilance most parents need only while their kids are infants and toddlers. We constantly consider and balance diverging opinions of professionals, family, and friends about how our children should develop or respond.

Intense emotion. We experience loss daily (whether or not we realize it)² and continuously cycle through grief. We do this throughout our entire parenting journey as our kids struggle, suffer, miss milestones, hit milestones (two decades late), or get rejected. In the meantime we have a life mismatched with what we had hoped for ourselves as parents.

Isolation. It's a tiring job to be caregivers as well as educators of all who interact with our families and our children. Sometimes we're isolated due to the nature of our children's special needs. Or we opt for isolation instead of having to explain ourselves—again—to someone who doesn't understand.

Fears about the future. For some of us, it's a very real possibility that our kids will die before we will. Or that they'll need a high level of care even as adults or after we pass on. We worry about how transitions in living arrangements will transpire, and fear how their care will weigh on our other children or extended family members.

Chronic stress unravels us. It agitates us and messes with our weight, sleep, memory, energy level, and long-term moods. It blanches our view of life, ourselves, our marriages, and our kids. Then again, I don't have to tell you that. You're already living it.

As a mom of four—the older two foster-adopted who, between the two of them, boast diagnoses of bipolar disorder, anxiety, ODD, ADHD, seizures, enuresis, encopresis, sensory integration problems, and speech and developmental delays—I’ve struggled hard and often with feeling numb and resentful. I’ve been angry over what I’ve lost: the family I imagined, the kids I’d dreamed about, the life where I didn’t have to do damage control with onlookers as my twelve-year-old goes ballistic in the middle of a supermarket parking lot. I’ve longed for the alternate universe where I don’t constantly struggle with feeling guilty, inept, lonely, and depressed, especially when I consider what life is like for my two younger children, who are growing up in a family with an intensity they never asked for.

The point here is not to add to your stress . . . or to languish in mine. It’s to recognize how real and intense our daily stressors can be, and how crucial it is to our health and well-being to learn to thrive despite them all. To do that will take something a lot stronger than we can muster through positive attitude, coping strategies, and punching the eighty-pound bag at the gym (although all of these do help!). No, it will take something much more powerful. Something supernatural, infinitely bigger than ourselves and the problems we and our kids face.



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THE SECRET TO DISSOLVING OUR STRESS

At the end of my rope five years ago, I got invited to a seminar on forgiveness at a retreat. “Oh good,” I groaned to myself. “Another super-spiritual topic that won’t relate to my daily life.” I did not want to go,

but my good friend was teaching it—the friend who’s prayed with me through fifteen years of ups and downs. So I sucked it up and went.

An hour later, I left the session feeling good that I’d supported my friend, but feeling even more angry at the process of forgiveness. Not because the talk was preachy or negative. She’d shared some of her own journey with forgiveness, and how she’d seen it follow three steps: (1) note the hurt, (2) choose to let it go, and (3) move on with life. She’d emphasized her own struggle with facing the truth that God requires us to forgive—even the hardest, most painful hurts—because we’ve been forgiven so much. All of it was familiar theology. Nothing earth-shattering or hard to understand. So, why were my fists clenched and hot tears streaming down my cheeks? Probably because the whole time I was thinking, “I’m sure this tidy little three-step model works just fine when someone cuts me off on the freeway. It really breaks down when I have frustrations, anger, and wrongs coming at me every day.” As my friend shared her presentation, my mind wandered to scenarios: if I were to forgive like this—acknowledging a hurt and choosing forgiveness each time my challenging kids give way to their darker sides, or a well-meaning friend recommends a basic parenting book to “solve” my parenting problems, or a doctor invalidates all the consistent work I’ve been doing with my girls—I’d be forgiving all day long. I’d never be able to think about another topic again!

“Just go ahead and end it here, Lord!” I whined.

He didn’t.

After that seminar, I finally felt the stress. Really felt it. Everything and everyone seemed totally unmanageable—a ton of bricks piled on top of me right where I sat. I’d prayed, confessed my own shortcomings, memorized Scripture, and chanted “I forgive [fill in offending person’s name here].” It wasn’t getting any easier to forgive. I felt desperate and distracted. My breath short, I felt anger and despair pressing in on me. I finally saw how I’d been pushing people away—it was simply too much work to build relationships when they often brought so much hurt, and my kids already needed 97 percent of my focus and energy.

I tried to ignore the turmoil caused by knowing God wanted me to forgive, and feeling like that was just one more item on an already overwhelming list of you’ll-never-get-these-done tasks. Over and over, like a

punch in the gut, the forgiveness idea kept resurfacing. In conversations, in books I read, in devotionals on which I reflected. Clearly I was missing something. But what?

Then, in one of the books, I came across this quote from Anne Lamott: “There [are] admonitions [everywhere] about the self-destructiveness of not forgiving people, and reminders that this usually doesn’t hurt other people so much as it hurts you. In fact, not forgiving is like drinking rat poison and then waiting for the rat to die.”³

Light flooded my mind. I saw it: my life was hard with special needs kids, the stress was killing me, and it was in large part because of *me*. I resented (withheld forgiveness from) just about everyone in my life instead of connecting meaningfully with them. I’d been living the emotional and—even though my high cholesterol hadn’t been diagnosed yet—physical reality of Deepak Chopra’s metaphor for resentment: “Holding on to resentment is like holding on to your breath. You’ll soon start to suffocate.”⁴

THE CHOICE TO TRULY LIVE AGAIN

At that point I had two choices: crumple under the weariness, hurt, and broken expectations, or learn how to forgive—release—others and myself to make space for something better. Something like a life again.

You have that choice too.

This book will help. It comes from my own (flawed!) journey to heal by spitting out the rat poison. By coming to understand forgiveness as an intentional way of life instead of another task to be done—forgiveness that acts like a filter in the midst of the ignorant comments of others, the disregarding tone of professionals, or my kids’ ongoing behavioral challenges. Forgiveness as an act of surrender that opens the door for emotional relief and divine help in every aspect of life.

This book also comes from another part of me: the certified life coach who wants to see you—to see all of us—get unstuck and enjoy life again. To support you in living the invitation of Hebrews 12:1: “Since we are surrounded by such a great cloud of witnesses, let us throw off everything that hinders and the sin that so easily entangles. And let us run with perseverance the race marked out for us.” Don’t you love that imagery? The

idea that we aren't confined to miserably carry the weights in our lives, or to crawl our way through the challenges we face? That we're invited to live for real—abundantly, with joy—to run with abandon together in freedom, no matter what we face?

And finally, this book comes from the experience of over seventy families who courageously shared their stories, struggles, and strengths in the online and phone surveys I conducted for this project. All our stories combine here to guide you as you discover what God can do when you choose forgiveness and healthy grief, and how these choices can change a family struggling with high needs kids into a family that thrives. They join the stories of hope from Scripture shared throughout this book to become that “great cloud of witnesses” who can spur you on in throwing off the stress weight that holds you down, to help you run with joy the unique race of life set before you.

Please allow these stories to come alongside and give you hope. Don't feel pressured to read from cover to cover all at once, but visit the sections that support you in the areas of greatest need right now. For me, the greatest need is often how I feel about God and His role in life's challenges. If that's you today too, go ahead and skip everything to go to chapters 14 and 15 and begin there. You can't do this book “right” or “wrong.” It is one hundred percent here to support you as you lay aside the life weights that would hold you back from running with joy and abandon.

I pray that you'll give freedom a chance.