



Hopeful Reflections on the Challenges
of Parenting Children with Special Needs

the
Life
We Never
Expected

FOREWORD BY RUSSELL D. MOORE
Andrew & Rachel Wilson

“What a great book! Andrew and Rachel’s surprise journey with their two autistic children opened the door to knowing God and his ways more deeply. They learned, or should I say experienced, that the gospel isn’t something you just believe; it is something you inhabit when God permits long-term suffering in your life. I’d recommend this book even if your family doesn’t have a child affected by disability—it is soul food.”

Paul E. Miller, Executive Director, see *Jesus*; author, *A Praying Life* and *A Loving Life*

“Weeping, worshiping, waiting, witnessing, and breathing. These are the constant rhythms of my life as a parent to a son with autism. These are also the rhythms of Andrew and Rachel Wilson’s life, beautifully and delicately illustrated in *The Life We Never Expected*. The Wilsons have managed to do what no other authors have—provide me with clear, promising hope as a special-needs parent and allow me the sacred practice of saying, ‘Me, too.’ Profoundly moving and deeply rooted in the love of Jesus, this book is exactly what I needed. It is a tremendous gift.”

Nish Weiseth, speaker; author, *Speak: How Your Story Can Change the World*

“This is a poignant and delightfully forthright book, written by parents who are still clearly raw from their experiences. Here is hard-earned wisdom, biblical realism, and winning sensitivity. Recommended for all in the throes of suffering and for all who would comfort them.”

Michael Reeves, President and Professor of Theology, Union School of Theology, Oxford, England; author, *Delighting in the Trinity*, *The Unquenchable Flame*, and *Rejoicing in Christ*

“Andrew and Rachel Wilson help us see how uniquely difficult it is to parent children with special needs. Their candidness is infectious, inviting us to do what the church should do: laugh with those who laugh and mourn with those who mourn. Parents of special-needs children will find compassionate solidarity, honest wrestling, voiced frustrations, and, most importantly, the gospel. Many will read this book and feel understood. Others of us need to read this book to understand, so that we can walk alongside those in the midst of hardship with compassion.”

Nate Pyle, Pastor, Christ’s Community Church, Fishers, Indiana; author, *Man Enough: How Jesus Redefines Manhood*

“In a striking display of honesty and depth, Andrew and Rachel Wilson explore the tension of faith and reality in this moving book. What I love most is that it’s written in ‘real time.’ They reflect on the pain and joy not after the fact but while they are experiencing it. *The Life We Never Expected* is one of those books you have to force yourself to put down. You will laugh, you will cry, and you will celebrate the goodness of God—even in the midst of suffering.”

Preston Sprinkle, Vice President of Boise Extension, Eternity Bible College; author, *People to Be Loved: Why Homosexuality Is Not Just an Issue*

“I am not a parent of children with special needs. In fact, I’m not a parent at all. Even so, I couldn’t put this book down. *The Life We Never Expected* is about so much more than parenting. It is about loss, lament, hope, humility, contentment, joy—and about finding God to be more than sufficient through it all.”

Karen Swallow Prior, Professor of English, Liberty University; author, *Booked: Literature in the Soul of Me* and *Fierce Convictions: The Extraordinary Life of Hannah More—Poet, Reformer, Abolitionist*

“This is a sweet and touching book—a testimony of parents’ love for their special, vulnerable children, and an extended meditation on the nature of the suffering that is part of the Christian life. Andrew and Rachel write with frank honesty and a sensitivity to biblical teaching about the expectations for life in a fallen world. I hope this little book will bring wise comfort to other parents facing similar challenges.”

Carl R. Trueman, Paul Woolley Professor of Church History, Westminster Theological Seminary; author, *The Creedal Imperative* and *Luther on the Christian Life*

“This is a helpful book both for those experiencing disability in their families and for those who love such families—not because of how the Wilsons are ‘dealing’ with disability but in how they rightly orient to our great and purposeful God. Having parented a child with multiple disabilities for more than two decades, I smiled regularly at their honest portrayal of life with disability. Anger, disappointment, and confusion along with delight and insight are offered in right measures. As both Andrew and Rachel point out, families like ours frequently do not experience the ‘great resolution’ about the circumstances of our lives, but we can always trust the promises of the One who made and sustains us and who will ultimately make all things new.”

John Knight, Director of Donor Partnerships, desiringGod.org

The Life We Never Expected

*Hopeful Reflections on the Challenges of
Parenting Children with Special Needs*

Andrew and Rachel Wilson

Foreword by Russell D. Moore

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For Pete Cooley,
a gift to the Wilsons, and to the church

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Foreword

Russell D. Moore

One of the most heroic men I ever knew was a member of a church I once served as minister. He had married very young, to a woman much older than he was. She had a son in his teenage years, and this man, not much out of his teenage years himself, was suddenly adjusting not only to marriage but to fatherhood to a developmentally disabled son. He told me that his wife, a sweet and patient woman, had been abandoned by the boy's father after he learned that his child was mentally disabled. The abandoning husband and father was an evangelical pastor. I winced at the scandal of this sorry ex-father, but I saw in the new father a picture of gospel courage and servant leadership.

This man reminded me of Joseph, who in taking Mary and our Lord as his own, faced the collapse of all his expectations for himself—and brought on himself the hostility of King Herod and the devilish tyrant behind the tyrant. He reminded me of James's admonition that pure religion is the kind that cares for widows and orphans in their distress (James 1:27). The man in my church never claimed that sort of hero status for himself. In his mind, he just did what a man does. He loved his wife, loved his family, and

did what it took to make it all work. He never called it heroic. But he also never called it easy.

Maybe you or someone you love has children with disabilities or special needs. Maybe you know the joy of loving a child who pictures Christ in ways the unbelieving world could never understand. But maybe you also know just how hard it is. Maybe you know that you are sometimes, maybe often, exhausted and depleted, with your nerves wrecked and your mind confused. Maybe sometimes you wonder if it's worth it or if you have what it takes. That's what this book is about.

Andrew and Rachel Wilson write about the fact that they didn't set out to be the parents of two children with autism. They didn't picture this on their wedding day. But God had something unexpected for them—as he has something unexpected for all of us, in some way or another. This book is honest. It doesn't flinch from telling the whole truth about the trials of parenting special-needs children. Andrew and Rachel don't present themselves as experts who have tracked out every bit of the terrain in order to tell you how easy it can be if you will just do it their way. No, this is a book by gospel people. They know that they need more than what they can perform or pull together. They need grace, every day, and they need power, every day. So do I.

But as honest as this book is about the hardships, it is brimming with hope and laughter. Andrew and Rachel need to know Jesus is with them, and indeed he is. This book doesn't tell you to try harder or to be more heroic. The book shows you how to come to Jesus, just as you are, for everything you need. That's good news.

Introduction

This is a book about surviving, and thriving, spiritually when something goes horribly wrong. In our case, that “something” was discovering that both of our children had regressive autism. This book, then, is a mixture of our story and God’s story, and the way in which his shapes ours.

For good reasons, we have to start a book like this with a few disclaimers. This is just our story (and it might not be yours). We’re new at this (we may look back in ten years and recant it all). Our experience of special needs is mainly limited to our children (and our highs and lows may be a drop in the ocean compared to what you are facing). We don’t know how to cope when children become aware of their disability (because ours haven’t yet) or how to balance the needs of special-needs children and their siblings (because both of ours are autistic). And so on.

So why, you might wonder, would two novices like us write a book like this? In short, the answer is that four years ago we were looking for something like this. We were looking for a book that was not just theology or autobiography but also something that talked about spiritual survival: how, in the early tumultuous years of coming to terms with special needs, we could cling to

Introduction

Jesus and even thrive in the midst of adversity. We couldn't find one, so we wrote one.

We've written with three types of people in mind. The first, obviously, is parents who have just been thrown a curveball—disability, for instance—and need encouragement to grip the Rock a little bit tighter (and to know God's grip upon them), even as the waves of life crash around them. Support groups are great. Friends who are going through the same things are invaluable. But we know that for us, nothing short of a Savior has been enough. We hope that as you read this, you will be encouraged and have your gaze continually redirected to him.

Second, we have written it for the family and friends of those who are raising children with special needs. We can't claim to know what it's like for everyone else, but we suspect some of our experiences will be shared by others—so if you're trying to come to terms with what's happening to people you love, this may be useful.

And third, we've written it for a broader audience, including anyone who is suffering at the moment and wants to know how to lament, worship, pray, wait, and hope. Our story may well be very different from yours, but the odds are that the ways God calls us to respond are fairly similar. So our prayer is that, whoever you are, this book will help you find God and lean on him in the storm.

We should also say, we took a deliberate decision to write while things are still raw for us, and that rawness (and inexperience) will probably come through these pages. Who knows? Maybe in twenty years' time, we'll be able to write a book about how God's purposes have been carefully woven through the fabric of our lives—and our family. But for now, we are feeling for them in the dark. Perhaps you are too.

The list of people who have helped us while we've been writing this volume—family, friends, educational and medical pro-

professionals, caregivers, social workers, church members, prayers, encouragers—is so long that it would take a whole book just to name them all. But there are a few people whom we just have to thank publicly. Our parents have been astonishingly supportive, helpful, generous, encouraging, flexible, creative, and sacrificial, and they have rescued us from many disasters, either by showing up to help or by taking the children so we could have a bit of space—and sleep. Our friends and fellow leaders at Kings Church, Graham and Belinda Marsh and Steve and Ann Blaber, not only encouraged us in the writing of this book but read through and commented on the manuscript toward the end of the process, which made the book much better than it would otherwise have been. We also received invaluable feedback from Debra Reid, Charles and Nikki Glass, and our excellent editor for the original edition published in the UK, Eleanor Trotter (at Inter-Varsity Press, Nottingham, England). Our friends Stephen and Emma Dawson found time in their busy lives to help us with the Q&A section, and for this, we are really grateful. And then there is the incomparable Pete Cooley, who has lived with us for two years and endured more early starts, shouts, glares, scratches, interrupted nights, meltdowns, and hissy fits than anyone should have to (and that’s just from Andrew). For them, and for the many others whose support has made life workable over the past few years, we will always be thankful.

Andrew and Rachel Wilson
February 2015

The Day of Deep Breaths

Rachel

Some days require a lot of deep breaths. That's true for every parent, but my guess is that it's intensified when you have children with special needs. For me, Thursday, August 4, 2013, was one of those days. Remembering it, even months later, brings on a weird combination of shudders, tears, and giggles.

We're on vacation, but it's an early start anyway. Zeke wakes at 4:30 a.m., and Andrew starts the day with him. (Vacations with our children are usually more exhausting than normal life, partly because the kids have their sleep routines messed up by being in a new place—in this case, a house belonging to friends who are away on vacation—and partly because the normal support, from school, nursery, parents, and friends, isn't there.) After an hour or so, Anna is up, the first DVD of the day is nearly finished, and breakfast is about to get started: Cheerios with milk for Anna, dry Weetabix (yes, I know) for Zeke. So far, so good.

Then Andrew wakes me up to tell me he's just vomited.

This happens sometimes, obviously. Men get sick. I suspect men who have been tired for two years get sick more often than most, and those surrounded by the kind of antics I'm about to

describe get sick more often still. But this is now round three of the second sick bug of the summer holidays—as in, Anna, then Zeke, then a two-week break when nobody is sick, then Anna, then Zeke, and now Andrew—and I’m beginning to find it annoying. I stare at him in dismay, hoping he’s joking. He isn’t.

I take a deep breath, get up, and go downstairs.

My appearance somehow makes it a matter of intense urgency that the *Oliver and Company* DVD case be found and handed to Zeke. We’ve now gotten used to the randomness of Zeke’s obsessions, but it can still be wearing—the *Oliver and Company* DVD case, not the DVD itself, and certainly (God forbid) not the video; the branded cover inside but removable; the location of the case in Zeke’s carefully laid-out line of twenty other cases; the explosive reaction to any interference with said line, especially from his sister; the unique and often incomprehensible words that summon the case to be brought (“Hoffer and Pumpnee! Hoffer and Pumpnee!”); the bouncing up and down and hand flapping that follow its arrival; and the rest. Knowing that a *no* will cause an outburst but a *yes* will cause repetitive behaviors for several hours, and it’s still only 6:15 a.m., I deny the request. Zeke repeats it. I deny it. (Bargaining at this stage is pointless.) Zeke repeats it. I deny it. Repeat eleven times. The inevitable outburst comes.

I take another deep breath.

After a few minutes of successfully engaging Zeke in a “normal” activity—sorting his cases, pulling the dog’s ears, or some equivalent—it occurs to me that Anna has been in the living room for a while but that things have gone suspiciously quiet. I walk down the hall to investigate. On entering the living room, I find Anna with her face submerged in the open-lidded fish tank, happily blowing bubbles into the water, while floating fish flakes bob about on the surface and bewildered guppies swim around her cheeks in confusion. I knew that Anna loved the sensory experience of face dipping, having done it all summer with paddling

pools and occasionally even sandpits, but it never occurred to me that she would do it in something so aromatically unpleasant and manifestly dirty as a fish tank. *No wonder everybody in this family gets sick so often*, I muse to myself. Another deep breath. For a moment, I wonder if it's worth grabbing a camera but decide instead to retrieve my three-year-old from the tropical waters and then set about drying the walls.

I return to the kitchen. Zeke, who had been happily rummaging through his cases, has somehow managed to slide a carving knife off the countertop and is running around the kitchen with it, whooping with delight. Another deep breath. At this point I have some difficult choices to make. Anna is dripping wet, and Zeke is at serious risk of either slicing his forearm or beheading the dog. Yet I know from experience that either shouting at him or running toward him to retrieve the knife will make him think we're playing a game and run away laughing, and that will instantly make matters much worse. So I amble nonchalantly toward him, with my body language saying, *This isn't a life-or-death thing; it's no big deal*, while my mind is racing with the thought, *This might be a life-or-death thing, and it's a very big deal*. Remarkably, it works. I retrieve the knife, put all the other knives out of reach, and head upstairs to get Anna into some dry clothes.

A few minutes later, more suspiciously quiet behavior, this time from Zeke, leads me back downstairs to the hallway, where I find the front door now wide open. I run out into the road in a panic, looking up and down the street for him, and then notice that he is sitting behind the car in the driveway playing with stones. Another deep breath. I take him back inside and double-lock the front door. The next few minutes pass without incident, and I manage to finish packing lunches, pile the kids into the car, and head off to a nearby adventure farm, where we arrive just as it opens in order to avoid Anna's greatest enemy: other people.

All things considered, the farm trip is a success. The children

cope, the meltdowns are limited, and although I'm on my own with them, nobody dies. But there are still a few incidents. The jumping cushion is surrounded by the shavings of recycled car tires, which are perfect for Zeke to sit there and chew while he decides whether he feels like jumping or not. Anna, who is mid-regression at this point, marches onto it with confidence and starts bouncing, but then another child makes physical contact with her, and she withdraws into shutdown mode, refusing to make eye contact, speak, or play for the rest of the morning. We go on a beautiful tractor ride: Zeke loves it and shrieks throughout, not because of the animals but because of the enormous rotating tires, but Anna buries her face in my shoulder and notices nothing. I carry her for the next two hours and reflect on the fact that, for all the face dipping, vomiting, front-door opening, and carving-knife waving my day has involved, much the hardest part of it is to fight the tears when I think of how my little girl has gone backward in the space of a year, from a chatty little person who plays and sings to a frightened baby who has lost nearly all her vocabulary and most of her social skills. Another deep, painful breath. I change her diaper, trying to give her a little privacy behind some play equipment, and while I'm there, Zeke obstructs the slide for the many other children who have now arrived, causing frustrated parents to look around for a responsible adult. It's tempting to pretend it isn't me.

Before heading home, we enjoy a picnic lunch, and the kids are peaceful and settled. While they're eating, I phone the hospital for the third time to hunt down a pair of reinforced Pedro boots¹ for Zeke, which no hospital department seems to be taking responsibility for losing, and check my messages to see if the latest blood test results for Anna are back, which they aren't. Another deep breath. On the way home, I think about buying milk, but since I can't take the kids into a shop on my own without—well, by now you can probably imagine—I decide that tea with soy milk isn't

so bad after all, and we go home without any dairy. I make sure to double-lock the front door when we get inside, check that the fish have survived their close Anna encounter earlier in the day, and then all but cover the tank with plastic wrap to make sure it doesn't happen again. I put on a DVD for the children and take one more deep breath.

One day, I say to myself, I'm going to laugh about this. I may even write a book about it.

Psalm 130

Out of the depths I cry to you, O LORD!
O Lord, hear my voice!
Let your ears be attentive
to the voice of my pleas for mercy!

If you, O LORD, should mark iniquities,
O Lord, who could stand?
But with you there is forgiveness,
that you may be feared.

I wait for the LORD, my soul waits,
and in his word I hope;
my soul waits for the Lord
more than watchmen for the morning,
more than watchmen for the morning.

O Israel, hope in the LORD!
For with the LORD there is steadfast love,
and with him is plentiful redemption.
And he will redeem Israel
from all his iniquities.

What Do We Do with Suffering?

A MEDITATION ON PSALM 130

Andrew

It is hard to think of a generation in history that has suffered less than mine. I'm a British millennial, and that means my life has been almost entirely free of the things that make life on planet earth awful: bloody wars, infant mortality, ethnic cleansing, tuberculosis, earthquakes, child trafficking, smallpox, the Osmonds. Yet the strange thing is, my generation struggles with the problem of suffering more, not less, than most of those who have gone before us. I have experienced far, far less pain and difficulty in my short life than almost anyone else in any period of history, yet I probably struggle with it—philosophically, emotionally, even theologically—more than the countless women who have lost babies in childbirth, lost husbands in war, and then died before they even reached my age. It's like the less we have suffered, the less equipped we are to deal with it.

That's why the Psalms are so powerful. They don't avoid the problem of pain, and they don't explain it away; they tackle it

head-on, and in doing so, they help us process our distress in ways that actually fit with the realities we're experiencing. They give us the words and emotions of seasoned sufferers, and they train us how to respond honestly, wisely, and well. And one of the best examples, as well as one of the most condensed, is Psalm 130. Walk through it with me for a moment.

The psalm begins where we all are supposed to begin when tragedy strikes—with weeping:

Out of the depths I cry to you, O LORD!

O Lord, hear my voice!

Let your ears be attentive

to the voice of my pleas for mercy!

This is an anguished start. It's not a careful, measured reflection on the nature of pain or an attempt to explain it. (We don't even know what the problem is at this point.) It's a cry from the depths, a desperate plea for mercy, accompanied by red eyes, sniffing, tissues, shaking shoulders, and jowls smeared with saltwater.

That's where our response to suffering is meant to begin. Many of us, fueled by fears, doubts, or insecurities, want to rush in with questions ("How could God let this happen to us?"), answers ("This must be happening because of *this*"), advice ("We/you should start doing *that*"), or plain silly comments ("It will be all right"). Others of us want to handle it by posting about it on social media, which runs the risk of confusing an instant reaction with a considered response. But there's a place for just wailing about it, like Jesus did when his friend died and like the psalmists seemed to do all the time. We need to learn—especially those of us from Western cultures where mourning is so understated—how to grieve in a way that gives due weight to what has happened to us. Otherwise, in our attempt to cope with the situation, we can trivialize the pain and so fail to deal with it properly.

Having said that, there comes a point when, after a period of weeping, the believer begins worshipping God in the darkness:

If you, O LORD, should mark iniquities,
O Lord, who could stand?
But with you there is forgiveness,
that you may be feared.

This line helps us see what the psalmist was crying about: he has sinned against God and needs mercy. That's why he starts reflecting on God's overwhelming grace and the ever-present offer of forgiveness. But even when our grief is of a different sort than this—prompted by sickness, death, poverty, persecution, or whatever—this is a wonderful way to respond to it. With the darkness all around us and the wounds still fresh, we lift our tear-stained faces to God and begin to worship him for the gospel.

Raising autistic kids is painful. This morning Zeke was up for the day at 3:30 a.m., Anna was grinding her teeth constantly from the moment she awoke, Zeke was shouting relentlessly about some cartoon character or other—when you haven't slept much, they all blend into one!—and Rachel and I were both on the verge of tears before the working day had even started. Some days we just look at our lives and think, *This is awful*. And sometimes it is.

Yet when I begin to worship God for the gospel, things start looking very different. Through the exhausted frustration, I remind myself, God has not “marked my iniquities.” He has forgiven me for every sordid, spiteful, and shameful thing I've ever done. He has rescued me from a life in which the crying and teeth grinding continue not just for a few hours on a Thursday morning but forever in eternity. He has treated me according to his mercy, rather than my performance. He has secured for me a future of eternal and unimaginable joy, which is thoroughly out of step with what I deserve. As I consider these things, and praise

What Do We Do with Suffering?

my Father for them, my weeping slowly turns to worshipping, just like the psalmist's does.

With all that said, though, the pain is still there. Celebrating the gospel is beautiful and is good for my soul, but it doesn't make me sleep more or cry less. Until God fixes everything, I'm still waiting:

I wait for the LORD, my soul waits,
and in his word I hope;
my soul waits for the Lord
more than watchmen for the morning,
more than watchmen for the morning.

You can't process suffering properly unless you remember that Christianity, like Judaism, is a religion of waiting. The world is not yet fixed. One day there will be no autism and no suffering whatsoever, but until that day, we wait. That's what makes life so exasperating sometimes, especially for those of us who are naturally impatient.

It's also what makes it full of hope, though. For the believer, waiting is not wishful thinking, as if we're waiting for a train or a parcel that may or may not come. Waiting for the Lord is a waiting grounded in certainty, based on his promise ("In his word I hope"), similar to the way watchmen wait for the morning. You don't get a lot of watchmen these days, but I've got a feeling they don't sit there at 3:00 a.m. thinking, *My goodness, this night's gone on a long time. Perhaps morning has been cancelled today! Maybe the earth has stopped at this particular point in orbit, and the sun is never going to rise again.* Watchmen wait for the morning not because they think it's coming but because they know it is. The night is dark, but the light always breaks.

That's how to wait for the Lord. I take great comfort from emperor penguins on this one: there's something about the way they

huddle together to protect themselves from Antarctic blizzards, each of them keeping a solitary egg above its feet through months of frozen darkness, that says, *This is almost unbearable, and it's almost worth quitting, but the sun is on its way. Hang in there, brothers. The light always breaks.* I want to wait for the return of Jesus like that. More than watchmen wait for the morning and more than penguins wait for the sunrise.

Finally, as the psalmist closes his short song, he begins witnessing, testifying about God's goodness to the people around him:

O Israel, hope in the LORD!

For with the LORD there is steadfast love,
and with him is plentiful redemption.

And he will redeem Israel
from all his iniquities.

None of us suffers alone. Even in those bleak times when nobody understands and the darkness is our only friend, there are multitudes of believers who have been there before us, and many of them still witness to us out of the shadows. "Whatever my lot, Thou hast taught me to say, 'It is well, it is well with my soul,'" said Horatio Spafford after his daughters had just died.² "The bud may have a bitter taste, but sweet will be the flower," wrote William Cowper, a poet who struggled daily with depression and suicidal thoughts.³ For forty centuries or more, worshipers of Israel's God have wept, worshiped, waited, and then borne witness to a steadfast love that cannot be broken, no matter what the circumstance. Their words are a profound source of comfort and encouragement to the rest of us.

As we come to terms with our pain and see the love of God at work in spite of it and even through it, we eventually reach the point when we can add our voice to that crowd of witnesses and testify to the ways in which *we* have found God to be faithful.

That's the destination we are heading toward eventually. One of the most exciting things that ever happens in our church is when ordinary people, who have suffered hardship and carried scars for months or years, come to the microphone and witness to the goodness of God through suffering. When we cut to the last page and see all that the Father has done, we want nothing more than to tell others about it: "With the LORD there is steadfast love!"

But much of our lives, and much of yours, is not lived on the last page. Many of us are so impatient to get there that in our pain, we flunk the weeping or the waiting (or, worse, foist our impatience onto others who are suffering, adding a dollop of guilt to the distress they are already experiencing). So rather than writing about how we get there as soon as possible—and if your story is anything like ours, you'll find you're continually making progress and then going backward anyway, as if playing a giant game of Snakes and Ladders—we've structured this book in five sections (weeping, worshiping, waiting, witnessing, and breathe) to try to help people who are processing each particular stage. Our story involves a confusing mixture of sadness, singing, silence, and celebration. So did the psalmist's. And chances are that yours will too. So we've tried to be honest about the challenges of each part, as well as the opportunities.

Don't get me wrong. Everybody loves it when the sun comes out and the female penguins return and the bereaved person finds contentment and the victim finds restoration and the autistic child flourishes. That's where the whole of creation is headed, little by little, and I'm so, so grateful that it is. But there are many times in between when being a penguin stinks. Trust me.



First
Cycle

The Orange

Andrew

Finding out your children have special needs is kind of like being given an orange.

You're sitting with a group of friends in a restaurant. You've just finished a decent main course and are about to consider the dessert menu when one of your friends gets up, taps his glass with a spoon, and announces that he has bought desserts for everyone as a gift. He disappears around the corner and returns a minute later with an armful of round objects about the size of tennis balls, each beautifully wrapped with a bow on top.

As he begins distributing the mysterious desserts, everyone starts to open them in excitement, and one by one, they discover that they have each been given a chocolate orange. Twenty segments of rich, smooth, lightly flavored milk chocolate—a perfect conclusion to a fine meal and a very sociable way of topping off an enjoyable evening. The table is filled with chatter, expressions of gratitude between mouthfuls, and that odd mixture of squelching sound and intermittent silence that you always get

when a large group is filling their faces. Then you open your present.

You've been given an orange. Not a chocolate orange; an actual orange. Eleven segments of erratically sized, pith-covered pulp, with surprisingly large pips in annoying places, requiring a degree in engineering in order to peel it properly, the consumption of which inevitably involves having juice run down to (at least) your wrists, being squirted in the eye with painful acid, and spending the remainder of the meal picking strands the size of iron filings out from between your molars. You stare at the orange in front of you with a mixture of surprise, confusion, and disappointment. The rest of the table hasn't noticed. They're too busy enjoying their chocolate.

You pause to reflect. There's nothing wrong with oranges, you say to yourself. They are sharp, sweet, refreshing, and zesty. The undisputed kings of the citrus fruit world—when did you last order a freshly squeezed *lemon* juice?—oranges are enlivening and flavorsome, filled with vitamin C, and far better for you than the mixture of sugar, milk powder, cocoa butter, and milk fat your friends are greedily consuming. With a bit of practice, you can probably peel them without blinding your neighbors. In fact, looking at the scenario from a number of perspectives—medical, dietary, environmental—you have actually been given a better dessert than everyone else. And you didn't have a right to be given anything anyway.

But your heart sinks all the same. An orange was not what you expected; as soon as you saw everyone else opening their chocolate, you simply assumed that was what you would get too. Not only that, but it wasn't what you wanted—you could pretend that it was and do your best to appreciate it and be thankful, but you really had your heart set on those rich, smooth, lightly flavored milk-chocolate segments. And because you're surrounded by other people, you have to come to terms with the sheer un-

fairness of being given your orange, while your friends enjoy, share, laugh about, and celebrate theirs. A nice meal has taken an unexpected turn, and you suddenly feel isolated, disappointed, frustrated, even alone.

Discovering your kids have special needs is like that.

Before we become parents, we have all sorts of ideas, expectations, and dreams about what it will be like. These ideas come from our own childhood (whether good or bad), from the media, and from seeing the experiences of our friends and relatives: pushing strollers with sleeping babies along the riverside, teaching our children to walk, training them how to draw with crayons rather than eat them, answering cute questions, making star charts, walking them to school. We don't look forward to the more unpleasant aspects of parenting—interrupted nights, diapers, tantrums—but because we know that they will come, and because we know that they will pass, we are emotionally prepared for them. Mostly, we daydream about the good bits and talk to our friends about the joys and challenges of what we are about to take on.

Then something happens. For some of us, it is at a twelve-week scan or at birth; for others, it is several months or even years later. But something happens that tells us, somehow, that all is not well. We'll talk a bit more about this later, but for now, it's enough to say that it rocks everything, and the entire picture of our lives, both in the present and the future, gets repainted in the course of a few hours. Gradually, as time starts to heal, we come to terms with the situation, and we learn that there are some wonderful things, besides the difficult and painful things, about what we've been given. Yet we can't help feeling isolated, disappointed, frustrated, even alone.

Special needs, like the orange, are unexpected. We didn't plan for them, and we didn't anticipate them. Because our children are such a beautiful gift, we often feel guilty for even saying this, but we might as well admit that we didn't *want* our children to have

autism any more than we wanted them to have Down's syndrome, cerebral palsy, or whatever else. Give or take, we wanted pretty much what our friends had: children who walked at one, talked at two, potty trained at three, asked questions at four, and went off to public school at five. We could have lived quite happily without knowing what Piedro boots were for, what stimming⁴ was, or how to fill out DLA (Disability Living Allowance) forms. So there are times when we're wiping the citric acid out of our eyes and watching our friends enjoying their chocolate, when it feels spectacularly unfair, when we wish we could retreat to a place where everyone had oranges, so we wouldn't have to fight so hard against the temptation to comparison shop and wallow in self-pity. We know that oranges are juicy in their own way. We know that they're good for us and that we'll experience many things that others will miss. But we wish we had a chocolate one all the same.

In our case, that feeling has become less acute and less frequent over time. Our appreciation for the wonders of tangy citrus and vitamin C has increased, and our desire for milk fat and cocoa butter has diminished. But in our story, so far, it hasn't disappeared. I'm not sure it ever will. And that's okay.

The Call to Sacrifice

Rachel

I received an email recently which ended with the words, “You are such a rich woman.”

Emails about the children don’t usually say that. Normally, they are of the sympathetic, sighing type: “I don’t know how you do it,” or “Things must be so tough for you.” So this one really caught me off guard. It gave my feelings of mild self-pity a resounding slap and made me want to let out a knee-jerk response: “Rich? I’m spent! Done! I have nothing left in my account to give.”

Yet the strange thing is that as I headed into the adult Christian life, “spending myself on behalf of the needy” was my aim, my life’s mission. As a teenager, I was inspired by the lives of missionaries past and present, men and women of faith like George Müller and Jackie Pullinger who made huge personal sacrifices for the sake of the poor and needy. I used to live on stories like Pullinger’s *Chasing the Dragon* (1980) and Sarah De Carvalho’s *The Street Children of Brazil* (1996). So considering that I have no

problem with sacrifice in itself and that I went into the Christian life with my eyes open, what's the problem?

The eye-wincing truth is that I had imagined my mission field might be a brothel of trafficked women or a schoolyard of African orphans. I thought the sacrifices would be more obvious and profiled and the yield (or harvest) that came from sleepless nights or leaving loved ones behind more tangible than they are. "Yes, I left my family and home comforts behind," I could imagine telling the breathless BBC correspondent, "but curing Ebola was worth it." Somehow, raising children with special needs doesn't have quite the same ring to it.

But the Lord is my Shepherd. I really do believe that. And for some reason, my Shepherd has led me to this field rather than that one. This mission field with these two beautiful, bottomless wells who require all my energy, strength, and patience. Sometimes it seems like a wasteful use of all these resources, resources that could have been used to feed the poor. Whenever it does, I try to remember my Shepherd sitting in a house a few miles from Jerusalem:

Now when Jesus was at Bethany in the house of Simon the leper, a woman came up to him with an alabaster flask of very expensive ointment, and she poured it on his head as he reclined at table. And when the disciples saw it, they were indignant, saying, "Why this waste? For this could have been sold for a large sum and given to the poor." But Jesus, aware of this, said to them, "Why do you trouble the woman? For she has done a beautiful thing to me." (Matt. 26:6–10)

Jesus, my Shepherd, doesn't seem to appraise value in the same way as I do. His spreadsheet is completely different from mine. He is interested in the wasteful expenditure of love and energy, just because it's in keeping with the sort of crazy love and sacrifice he showed in his life and death. His call to sacrifice is the same

whether I'm standing in an African field or in a kitchen with a child who for the 365th time this year needs to be cajoled into finishing a few spoonfuls of noodles. This certainly isn't the sacrifice I would have chosen to make. But I remember standing in a meeting a few years ago and clearly saying to God, like Ruth to Naomi, "Your people shall be my people" (Ruth 1:16). Well, these two are his people, and now they're my people.

For those of us who are mothers (and fathers), God wants us to esteem the field he's given us. It's not a tiring distraction from the true mission field we should be tilling; these are *our* people, for us to reach and for us to be trained and transformed as we do. Not only that, but in our giving, as we willingly lay down our lives, he smiles on us, because as Christ explained, "Whatever you did for one of the least of these brothers and sisters of mine, you did for me" (Matt. 25:40 NIV). All the sacrifices, the diaper changing, the feeding, the dealing with meltdowns—they cannot be worth it if they're just for our children. But they're not. Ultimately, they are a perfume poured out for him.

It can be so easy, though, to look for more immediate sources of praise. Eight years ago, I did an internship program for a human rights organization in Washington DC. On the first day, the CEO welcomed us in a staff breakfast, and as part of his address, he handed us each a small trumpet key ring. He told us that there would be times when, out for drinks with interns in corporate law or accountancy, it would suddenly be tempting to belittle their sacrifices or hard work by subtly (or not so subtly) reminding them that while they work to make rich clients richer, we work long hours to free slaves. At times like these, he told us, we were to look at our trumpet key rings and make a conscious choice not to blow our own trumpets. Faced with a room of young, passionate, but competitive interns, it was a pretty perceptive welcome.

I still think about that trumpet. And there are days, even now, when it is tempting to blow my own trumpet, whether by looking

for recognition in the wrong places or by belittling the parenting trials that the people around me face. In a room full of women bemoaning the fact their children won't try broccoli, it can be tempting to throw in a conversational bomb like "Yes, but does anyone have any strategies on stopping smearing?" The truth is, as a parent, you wield a certain amount of power to make people feel bad about their own challenges or to make them live in awe and admiration of yours. Being open and honest with trusted friends is great, as is receiving their encouragement and affirmation. You need it! But the life sacrifices are ultimately for an audience of One.

Parenting in a daily willingly-laying-down-your-life way is a powerful opportunity to reflect and enact what the gospel truly is. But it is just a reflection, a role play, if you will—because there is no humbling moment, no public humiliation or social isolation that matches what Jesus experienced at the cross. We have a High, Priest who fully sympathizes with all our weaknesses and gave himself up as the centerpiece of our faith. Giving up our lives for others is the centerpiece of our faithfulness.⁵ The call to Christ is a call to sacrifice—to suffering, death, and burial—and through that sacrifice, to resurrection and fruitfulness. So yes, today, I am spent. But in the gospel, I am rich. My friend was right.

The True Battle

Rachel

If, in the weeks that followed Anna's diagnosis, you had taken a page out of the *News of the World's* book and hacked our home phone, you would have had no doubt that a battle was underway.⁶

I ran around like a headless chicken. I trawled the Internet for news of funds, equipment, and services to which we might be entitled. I spent hours documenting the children's behavior and needs. I quickly got on first-name terms with several medical secretaries. I chased down professionals for the latest reports and the soonest-available appointments.

As it happens, I think that all the hard work I did was, in the end, in the children's best interests. But—and this is one of the key points of the book you're now reading—the true battle was elsewhere.

You see, as important as school places and car seats and strollers and boots are, they are peripheral. They sometimes look like the most important thing going on in a particular day, but they never are. All of them, one day, will expire, pile up in a landfill

somewhere, be eaten by moths, decay, or degrade. And if I don't realize that, they will continue to distract me from where the true battle is being fought: in the two-pint, gray lump of squidge behind my face.

Of the many helpful things I have read during our journey with the children, a paragraph from Rachel Jankovic, who at the time of writing had five preschool children, rises to the top of the pile. She writes,

If there is anything I have learned in the course of my fast and furious mothering journey, it is that there is only one thing in my entire life that must be organized. The kids can be running like a bunch of hooligans through a house that appears to be at the bottom of a toaster, and yet, if organization and order can still be found in my attitude, we are doing well. But if my attitude falters, even in the midst of external order, so does everything else.⁷

She is so right. I could have a rolling schedule of every therapy under the sun—private drumming lessons, funding for horse handling, a private school place, even a fully equipped sensory room in my house—but if my mind is not settled toward God as the author of it all, and if I am not putting him first, I might as well quit. It will all be in vain; it won't bring me any peace, and the true battle is being lost.

The reverse is true too. Zeke could be running laps and flapping his hands in one corner, Anna could be wandering in circles and grinding her teeth in another, and the floor between them could look like the results of an explosion in a children's center. But if, through it all, my thoughts are ordered, and I am able to see my circumstances in a God-shaped way, then the true battle is being won.

What is exasperating is this: I can have days in which I win several fake battles, but in doing so, I lose the true one. The fake

battles are a whirlwind of phone calls, government services, websites, more phone calls, forms, applications, more phone calls. And each of these can distract me from the true battle, which, more often than not, is not fought that way. Frequently, the weapons of the true battle include silence, prayer, thought, clinging onto a recently read Scripture passage with my fingernails, singing through gritted teeth, reading a prewritten prayer out loud, reaching for Jesus through the mist of confusion or unanswered prayer, stilling myself in his presence, and remembering that he is good and faithful and kind. So distinguishing between the fake battles and the true one, between what I can do and what I must do, is critical. Phone calls and social workers can wait. Centering my thoughts on God cannot.

I love my kids most not by loving them the most but by first loving God. As soon as I take my eyes off him and my attitude falters and I begin to believe that I alone must push for them and control their destinies, the unbearable weight of playing God soon becomes apparent. When I put my eyes back on the One who always deserves my attention, then whatever fake battles are being lost around me, the true one is being won. It makes all the difference.

Individualitis and the Dung Gate

Andrew

For many years, I have suffered from individualitis. It's a debilitating yet curiously common disease of the soul, and it's especially common among young, rich, Western people. It comes in many forms, but its primary symptom is the unshakable belief that the world is mainly about *me*.

I don't know where I caught it. It could have been at boarding school, where I was taught that I should "blaze my trail," and that we were probably going to end up being masters of the universe. It could have been at university, where academics and recruiters insisted that the world was our oyster. (It isn't, of course. It's an enormous ocean, much of which is dark and unknown, and it's got plenty of oysters, as well as thousands of creatures that are just like you, and millions of creatures that want to eat you, and billions of creatures who will never know who you are.) It might have been with me from birth. It might even have come from the

church; I remember singing songs about my personal destiny and how I was going to be a history maker and how although everybody else was ordinary, I was going to be different. Probably, it was a mixture—but wherever it came from, I caught it.

The really worrying thing, as I look back, was that I didn't realize it was a problem. It wasn't until much more recently that I came across a paragraph from Carl Trueman that punched this whole way of thinking on the nose:

The belief that we are each special is, by and large, complete tosh. Most of us are mediocre, make unique contributions only in the peculiar ways we screw things up, and could easily be replaced as husband, father or employee, by somebody better suited to the task. . . . [Yet] far too many Christians have senses of destiny which verge on the messianic. . . . Put bluntly, when I read the Bible it seems to me that the church is the meaning of human history; but it is the church, a corporate body, not the distinct individuals who go to make up her membership. . . . My special destiny as a believer is to be part of the church; and it is the church that is the big player in God's wider plan, not me.⁸

The man's got a point.

But I had never seen it that way. I thought I *was* special, unique, irreplaceable. In fact, individualitis affected every area of my life. I thought individualistically about purpose (“my purpose in life” rather than “our purpose in life”) and Scripture (“this passage is for me” rather than “this passage is for us”). I thought that way about the church (which serves me), the gospel (which is about rescuing me), cultural change (which happens when great individuals rise up and do something), and evangelism (which is about individual people sharing their stories). Most of all, I thought that way about *calling*: Rachel and I both had one, and it was up to each of us to find out what our own callings were and

then fulfill the roles that only *we* could. It was encouraging to hear just how much of God's big plan depended on *us*.

Then our lives hit the wall. You know all about that by now. Suddenly, the future we had imagined—saving the world through preaching, writing, advocacy, intervention, and traveling around the globe—was completely reconfigured. Before we found out about the children, it was sort of imaginable that we could be fruitful for God on our own. (Sort of imaginable.) But from that point on, it became utterly *unimaginable*. These days, we can't even get through the day without the church, let alone save the world. We are totally dependent on a community of people—people who help, encourage, pray, serve, take responsibility—to be fruitful in any way at all. Without them, we're like branches without a tree, parts without a body, stones without a building. Which is just how God wants it.

One of my biblical heroes is a guy named Malchijah, who pretty much debunks individualitis on his own. You've never heard of him. Almost nobody has. He sits, marooned, in the middle of an incredibly long and dull list of names in Nehemiah 3, which is a chapter about the wall of Jerusalem being repaired. It lists all the builders, one by one: Eliashib, who built the Sheep Gate; the sons of Hassenaah, who built the Fish Gate; Hasshub, who helped repair the Tower of the Ovens; and so on. And in verse 14, buried in with all the others, is Malchijah the son of Rechab, who repaired the Dung Gate. The *Dung Gate*. I'll just let that sink in for a moment. (I imagine he would rather have been allocated the Tower of the Ovens.)

The reason why Malchijah is my hero is this: he wasn't a hero. He didn't lead Israel, kill any bad guys, or have a book named after him. We don't actually know anything else about him. All we know is that he spent a short period of his life doing something very mundane, very smelly, and very unnoticeable: he fixed a Dung Gate. Yet in his mediocre, ordinary way, Malchijah—

along with Eliashib, Hasshub, the sons of Hassenaah, and all the others—established the kingdom of God on earth.

I say that because ancient cities depended on their walls to keep them safe, and their walls were only as strong as their weakest point. So if 98 percent of the wall of Jerusalem was perfectly restored and the Dung Gate was a tumbledown mess, then an enemy could simply attack there, and the city would fall. There is no use whatsoever in building *part of* a wall or having a wall that is *mostly* secure. (Just ask the guys who built the Maginot Line.) So if Malchijah hadn't done his bit—his mundane, smelly, unnoticeable bit—Jerusalem could have fallen, and Israel would have been defeated, and there would have been no kingdom, no Jesus, and no gospel. Yet until just now, you had never heard of him.

I was always inclined to think that God's purposes came about through great leaders, unreasonable men taming the world and defying the odds. Traveling preachers, justice campaigners, people like that. Mostly, however, they don't. They come about through millions of unnamed people doing unheard-of things, in unnoticeable ways, to the glory of God. Repairing a wall. Teaching a classroom of seven-year-olds. Sweeping a street. Running a business. Raising autistic children. Fixing a dung gate.

That, for most of us, should be hugely encouraging. In God's global mission, the role of extraordinary people doing exceptional things is probably far smaller than we imagine—and the role of ordinary people doing everyday things is certainly far greater than we imagine. If you think you're exceptional, that will come as a nasty shock. But when you get mugged by life and find out just how ordinary you are, it's thoroughly liberating. Carl Trueman was right: "My special destiny as a believer is to be part of the church; and it is the church that is the big player in God's wider plan, not me."

The Special-Needs Beatitudes (What Jesus Might Have Said)

Rachel

Jesus talked a lot about an upside-down kingdom. The weak would become strong, and the mighty would be brought down; the humble would be exalted and the proud humbled; the poor would be blessed and the rich undone; the first would be last, and the last would be first. Much of this way of thinking is captured in the beatitudes in Matthew 5. I was thinking and praying about this one day, and I started writing down some special-needs beatitudes on our whiteboard. These aren't in the Bible, obviously, but they reflect what I think Jesus might say about children (or adults) with additional needs:

Blessed are the autistic, for theirs is the kingdom of heaven.

Blessed are the tube-fed, for they will be comforted.

Blessed are the nonverbal, for they shall inherit the earth.

Blessed are the hyperactive, for they shall be satisfied.

First Cycle

Blessed are the wheelchair-bound, for they shall receive
mercy.

Blessed are those with mental-health issues, for they shall
see God.

Blessed are those in regression, for they shall be called
children of God.

Blessed are those who cannot communicate or understand,
for theirs is the kingdom of heaven.

“This isn’t a book that’s going to tell you to pull yourself up by your bootstraps and try harder. This is a book for those who are on the floor, weeping, because they need to know Jesus is with them.”

RUSSELL D. MOORE, President, The Ethics & Religious Liberty Commission

Sometimes life throws you a curveball.

Andrew and Rachel Wilson know what it means to live a life they never expected. As the parents of two children with special needs, their story mingles deep pain with deep joy in unexpected places. With raw honesty, they share about the challenges they face on a daily basis—all the while teaching what it means to weep, worship, wait, and hope in the Lord. Offering encouragement rooted in God’s Word, this book will help you cling to Jesus and fight for joy when faced with a life you never expected.

“This book is about so much more than parenting. It is about loss, lament, hope, humility, contentment, joy—and about finding God to be more than sufficient through it all.”

Karen Swallow Prior, Professor of English, Liberty University

“I’d recommend this book even if your family doesn’t have a child affected by disability—it is soul food.”

Paul E. Miller, Executive Director, see Jesus; author, *A Praying Life* and *A Loving Life*

“The Wilsons have managed to do what no other authors have—provide me with clear, promising hope as a special-needs parent and allow me the sacred practice of saying, ‘Me, too.’ This book is exactly what I needed.”

Nish Weiseth, speaker; author, *Speak: How Your Story Can Change the World*

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PARENTING

