# DISRUPTED JOURNEY

## Walking with Your Loved One Through Chronic Pain and Illness

NATE BROOKS



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## To my wife, Kate, whose steadfastness in suffering I aspire to,

and

to Jeremy and Alicia Wright, faithful friends, fellow travelers, sanity-keepers.

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### INTRODUCTION

DON'T KNOW THE specific story that has led you to pick up this book, friend. I doubt that you ever expected to be holding a book on your place in the mystifying world of chronic pain and illness. I certainly never imagined I would write one. But the fact that this book is in your hands means that you and I have watched Plan A for our lives evaporate, replaced by Plan B or Plan C or some other letter terrifyingly deep in the alphabet.

I want to start by telling you I'm sorry. I'm sorry that this is the path you must walk. I'm sorry you have to watch your loved one suffer. I'm sorry that you suffer in a hundred often unseen ways as well.

One day a couple thousand years ago, Jesus was asked by a lawyer what he considered to be the most important commandment given by God. "Love God with all your heart and love your neighbor as yourself," he said. That sounds so simple, doesn't it? But we know from our experience that simple commands often prove to be the hardest of all to follow, even in the best of times. This book is a meditation on trying to faithfully live out those oh-so-simple-sounding commands when life veers far away from being the best of times. How do we love God when he in his providence has allowed life-altering pain and illness into our

loved one's life? And how do we love our loved one well when they are wrestling with their whole world being turned upside down?

If you're there, my hope is to offer you encouragement through this little volume. Those who suffer from chronic pain and illness often express that they feel forgotten or unseen by those around them. I'm grateful that more resources are becoming available to support those whose bodies feel deeply the sting of the curse. But for every person whose life is crumbling due to chronic pain or illness, there is at least one other person who loves them and must wrestle too with the reality of their own lives turning out very differently than they expected. If your life has been changed and disrupted by the suffering of someone you love, this book is for you. I can't say I'm an expert on everything you've gone through and are going through. There are many whose lives are more difficult than mine. But I hope we can walk together for a little while on this path and encourage each other.

#### WATCHING MY OWN HOUSE BURN DOWN

I am by vocation a counselor and professor. I specialize in caring for individuals and families caught in cycles of abuse and trauma. As such, my life is often a front-row seat to the terrible evils that people suffer from and inflict on one another. I've often thought that counselors and firefighters have a lot in common—we run into burning buildings to help, then retire to the station once the task is done.

But this book doesn't come from that professional place. This book isn't the equivalent of a book by a firefighter on the methods of extinguishing residential blazes. It's a meditation from a firefighter who has watched his own house burn down and been unable to stop it.

My wife Kate and I met at a tiny high school on the central coast of California. It took me ten years to ask her out, but once I did I quickly realized that I should have used that past decade quite differently. She was the best of everything I never knew I needed—daring, spunky, always on the edge of doing something just a bit crazy. She sang. She danced. She spoke her mind. Her love for Jesus radiated out from every fiber of her being.

We tied the knot on one excessively warm afternoon in June 2013. Little did we know that the defining two words for the next eleven years and counting would be *chronic pain*. Our descent into that world began just six months after that happy day, and we've never made it back out of the hole.

I don't always know how best to describe what's gone wrong. There are so many levels—levels that undoubtedly you experience as well.

I could talk about medical details, a path littered with all manner of doctors and medications and hopes raised and dashed over and over again. Gone are the days of running together, the lengthy hikes in the woods, the ordinary easy movement and touch that framed our lives before.

I could talk about rewriting every category of life as chronic issues entrenched and we had to surrender to a new reality over and over and over again. Gone are the piles of homeschool curricula and tidy budgets and any semblance of a "normal"-looking two-parent household.

I could talk about the dark nights of the soul when the things we thought we knew and understood about God and ourselves and good theology were pressed far beyond what we could have ever imagined. Gone is the uncluttered relationship with God where his rule means that things generally turn out okay and the standard of human life is happiness.

I could talk about the pummeling effect chronic pain and illness have on relationships, of well-meaning people (who seemingly ought to know better) insisting that greater faith or essential oils can set your life back to normal if you just would truly believe. Gone is the feeling of being understood, of having a normal life that most people can relate to.

I could tell you that the first prayer my two-year-old daughter uttered on her own was "God, Mommy feel better?" Or about the times I have had to explain to my sons' teachers that, no, their mother wasn't dying; our boys were just processing their fear that she might. Gone is my kids' innocence as they inhabit a world where they learn of debilitating pain before My Little Pony or Pokémon or the other stations along the way of growing up.

Chronic pain and illness are the backdrop for the movie of our life. They were there when we were newlyweds trying to figure out how to take two lives and blend them into one. They were there as we welcomed three kids into the world and lived in four states. They were there as we watched God take Kate's father home to be with him. They have wound their way through every event, every milestone, every day of our existence. And barring something unexpected, we have about forty-five more years to go.

#### THE FASTEST OR THE LASTEST

Writing a book on suffering is a daunting task. You may have drunk far deeper from the cup of suffering than I have. I marvel at your strength and how God upholds you. Or you may wonder if you've earned your place at the table. Sure, we have our struggles, but this idea of entire-life-rewriting pain and illness is farther into the cave than we've stepped. It's true that some of us have heavier

burdens to carry than others. But at the end of the day, each of us whose spouse, child, parent, sibling, or friend is afflicted with chronic pain and illness carries burdens. We're a community of people trying to figure out how to live a life that's no longer Plan A and endure in love like Christ does for us.

My favorite sport is long-distance trail running. (Strange, I know.) Right now, the top athlete in the sport is Courtney Dauwalter. She's rewritten every record in the book, including setting the course record at the Ultra Trail du Mont Blanc, a 106-mile race, by over an hour. (That's the equivalent of a team winning the Super Bowl 43–8.) For all her athletic achievements, I find her view of other runners even more impressive. She often talks in interviews about how she's not convinced she's the most impressive athlete in the field. After breaking the Tahoe Rim course record, she noted that, for her, "the best part of it all, I think, [is] cheering people in. We all cover the same trails. It doesn't matter what pace you did; everyone did 205 miles out there."

I've found Dauwalter's advice helpful in so many ways as I meet new friends whose lives have been disrupted by a loved one's diagnosis of chronic pain and illness. There's no "fastest or lastest" in the world of suffering. We all have our unique struggles and challenges. Wherever you are on the road of learning to rewrite your life, my hope is that this book meets you.

#### FAMILY STORIES AND FAMILY PRIVACY

Before we turn to the first chapter, I do need to say one more thing. This book is my book, interwoven with parts of my story. It's not my wife's story. She'll float in and out of the pages as a prominent character, and I'll talk about some of what's happened to her.

I've chosen not to share many details about what exactly has gone wrong physically for her. Her story involves the sudden onset of debilitating health issues whose origins have never been understood as well as medical interventions that did significant, permanent damage for which there is no cure. But the specifics are her story and hers to hold. It's not my place to share them in a book that the whole world can read. I know you likely face this tug-of-war as well in your own community—how much do we say and to whom?

I appreciate your willingness to give grace as I walk the tightrope of giving enough detail to be real yet not so much detail as to transgress wise family privacy. Kate is a counselor too, and she has read and approved everything in this book. In many places she's helped me better describe her and my experiences. We both want our experiences on the road we've walked to be used by God to encourage others navigating the rocky paths of chronic pain and illness.

As you turn the page and begin chapter 1, know that I'm praying for you. Your journey is one you never expected to set out on, but the way your faith and love compels you on is amazing.

## 1

## WHEN SUFFERING ISN'T A SEASON

I wish you could share my view with me as I work on this little book. We live on a heavily wooded lot, and it's fall. As a Californian transplant to the East Coast, I've only recently come to experience how lush green trees can be swallowed up in just a few days' time by the fiery beauty of thousands upon thousands of leaves spending their last few days of life beaming forth striking yellows and reds and every color in between. Fall in California rarely lasts more than a few days. Blink and you'll miss it. But here in the Carolinas, I've come to appreciate the varied seasons offered by our new home.

Fall turns into winter, those same trees bundled up tightly against the brisk temperatures awaiting the return of some warmth to stir them. Winter is crisp and clean, and then it is followed by the rain and storms and beauty of a Carolina spring. Trees stir, the air warms, new growth emerges. Eventually new

growth matures, and the hot stickiness of summer begins its reign. The whine of cicadas keeps watch over my kids as they splash in the watering hole that collects in the backyard stream's lazy meandering.

Seasons come and seasons go. Each has something to complain about; each has much to be cherished. When I'm shivering and scraping ice off my windshield, I can know that sooner or later the layer of frost will be replaced with fresh warmth.

I don't know when we decided that *season* was the best word to attach to our experience of suffering. Do a quick search and you'll come back with an armload of books that aim to comfort you, equip you, and even prepare you for "seasons of suffering." The prayers that spill out of relationships ask God to "comfort and keep my brother (or my sister) as they walk through this season of suffering." And truly there are kinds of suffering that are seasons. We walk through the valley of the shadow of death and emerge out the other side.

But there are other kinds of suffering, other sadnesses, whose paths do not ever emerge from that dark valley. Each step is another step into suffering, and—though there may be times when the road is just a bit better—the road never finds its way out of the dismal swamp. So long as breath fills your lungs, there is no hope that the season will change. Winter is here, and it is not leaving. Here in this place, suffering isn't a season. It's become your life's climate.

#### FOR EVERYTHING THERE IS A SEASON?

God has left us more than a few mysteries in his Word, and one of those is who penned the book of Ecclesiastes. He signed off on his book as "Quoleth," which translates as "the Teacher." Tradition and quite a few clues scattered throughout the book point to King Solomon as its author, but we aren't completely sure. Regardless of which ancient writer handed his wisdom down to us, the Teacher paints a picture of life that leaves us feeling uncomfortable. His opening words certainly set a mood: "Absolute futility,' says the Teacher. 'Absolute futility. Everything is futile'" (Eccl. 1:2).

Some twelve chapters later, there hasn't been a great deal of movement in the Teacher's view of reality. He's explored everything a human being could hope to indulge himself or herself in, and yet when he drops his conclusion he's in the same place he began: "Absolute futility,' says the Teacher. 'Everything is futile'" (Eccl. 12:8).

I don't know about you, but I find his perspective on life unnerving. Even more troubling is that the Bible calls him a "wise man" who "sought to find delightful sayings and write words of truth accurately" (Eccl. 12:9–10). The Teacher's not an optimist when it comes to surveying the kinds of lives that are available to human beings. He's tasted all the joys, and he ends his life telling anyone who will listen that his treasure trove of happiness cannot undo the emptiness of life.

The futility of life is the expectation of the Teacher. Left with two choices, instead of ending up with "rage, rage against the dying of the light," he says, "Remember your Creator in the days of your youth: Before the days of adversity come, and the years approach when you will say, 'I have no delight in them'" (Eccl. 12:1). There's a certainty, a finality, to the Teacher's words. The years will come when adversity piles up so high that you'll say, "I have no delight in them anymore."

It's easy to forget these words when life is full of happiness. There's a lot of things in life that bring joy. Good food, family, ministry, athletics, friends, nature, marriage, vocation—all are delights for our enjoyment. But the Teacher wants us to remember that even in the highest of all joy, days of adversity are coming. He's so sure of this that he wants us to make sure we understand that life is not a grand story in which things are always working from sadness to happiness, from brokenness to wholeness, from dark to light.

For everything there is a season, and a time for every matter under heaven:

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a time to be born, and a time to die;
a time to plant, and a time to pluck up what is planted;
a time to kill, and a time to heal;
a time to break down, and a time to build up;
a time to weep, and a time to laugh;
a time to mourn, and a time to dance. (Eccl. 3:1–4 ESV)
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Maybe it's from this passage that we picked up on the idea that suffering is supposed to be a season. After all, the Teacher says there's a season for everything under heaven. There's a time to mourn and a time to dance. There's a time to weep and a time to laugh. Bad things are replaced by good things. See?

But as much as we may wish this to be the case, it's simply not what the Teacher would have us remember. Because for every line that moves from sorrow to joy, there's a line that moves the opposite way. There is "a time to search and a time to count as lost; a time to keep and a time to throw away . . . a time to love and a time to hate" (Eccl. 3:6, 8).

Every line of the Teacher's words is true. There is a time for mourning and a time for dancing. But his point isn't that mourning is *replaced* by dancing. The time of breaking down

doesn't automatically blossom into a time of building up. These seasons aren't sequential, a promise that things are getting better. Sometimes they will. But for every sorrow that turns into a joyful reel, there will be love that will fall away into its opposite.

We may be tempted to look at this passage and say, "Well, we know that our ultimate destination is in heaven, so *all* suffering truly is just a season." And I certainly don't disagree with that. Indeed, the Teacher is really quite insistent that we remember God in the days of our youth because when all is said and done "the spirit returns to God who gave it" (Eccl. 12:7). But that's not what we typically mean when we talk in church or with friends about suffering being a season. We mean that this trouble will pass and we'll be able to go back to living a generally happy life here on earth.

That's why the Teacher's words are so disquieting. Someone who speaks of absolute futility doesn't sound like he expects life to be generally happy. There's a finality to his expectation that human life terminates in deep suffering. Even worse, when we start searching the other pages of Scripture, we find that this kind of thinking isn't limited to an author we can't quite identify with 100 percent certainty and who wrote a very long time ago.

Jesus assures his disciples, "You will have suffering in this world" (John 16:33). Paul begs God to remove his "thorn in the flesh," which makes his life so miserable that he names it a "messenger of Satan to torment me" (2 Cor. 12:7). Elsewhere Paul reminds the Roman Christians that God's creation is "subjected to futility" and "groan[s] together with labor pains." Every reader of that letter would look down at their hands and bodies and realize that they are part of that groaning creation, living in enfleshed futility as decaying nerves and tendons and gray matter cry out, waiting for "the redemption of our bodies" (Rom. 8:20, 22, 23).

God's words to us don't set the expectation that suffering is anything other than what we should expect on earth. But if I'm honest, suffering isn't my default expectation. I don't know if you're like me, but I read what I've written above and my heart starts to churn. No. No. Yes, that's in the Bible, but we've moved past the days when that kind of suffering was normal. We have advanced medicine. We're more enlightened now. Things should be better. But these expectations that suffering will be merely seasonal are born out of an environment in which prosperity, tranquility, and ease are the expected norm of life. Sure, suffering is real, but give it enough time and the medicine will work, the shivering frosts of winter will burst out into buds and blossoms in the warmth of spring. Just hang in there; just keep going. Because it will get better.

#### LIFE IN THE CLIMATE OF SUFFERING

Chronic pain and illness don't work that way, do they? They are, after all, chronic. If you're holding this book, you know just as surely as I do the ever-present hope of just one more doctor's appointment. *Maybe*, just *maybe*, this doctor, this procedure, this test, this claims-have-not-been-evaluated-by-the-FDA set of pills will prove to be *the* answer. Surely this must be the missing piece of the puzzle, because puzzles always have all their pieces and suffering is just a season and must fade.

But sometimes there's just no other puzzle piece that can be found. In C. S. Lewis's *The Lion, the Witch, and the Wardrobe*, little Lucy gasps when the fawn Tumnus sadly describes his land as one where it's "always winter and never Christmas" under the cruel reign of the White Witch.<sup>2</sup> But life in the land of chronic pain and illness moves one step beyond that grim, frosty reality. Even when the beautiful day of Christmas happens—a short,

brilliant reprieve from symptoms, a special event or trip, or the delight of a virtual call with a friend who just gets it—it always goes back to being winter. It's Narnia at the North Pole, a world where the snow and the frost and the ice just *are*.

Here, suffering isn't a season; it's the climate. And—as one friend quipped to me—so often, as with our climate today, things just seem to be getting worse. A sudden downturn becomes the new normal. The hours of pain lengthen, and the fierceness of pain deepens. An accident or injury maims further. "Surely it'll get better" turns to "I hope it will get better," which then turns to what we thought was unsustainable becoming the new normal.

#### THE EMOTIONAL PROSPERITY GOSPEL

I come from a theological tradition that has long recognized the folly and danger of the prosperity gospel. Our radar is well attuned to seeing through preachers living gilded lives, promising that God will throw open the storehouses of heavenly wealth or success or power in exchange for money given in faith. But while we've chased away the economic prosperity gospel from the front door with an eye roll and rightly interpreted Bible passages, far too often we've let in his cousin through the back door. We know enough to reject a gospel that proclaims faith begets wealth. We're far more susceptible to a gospel that believes faith begets unruffled contentment. That gospel, the emotional prosperity gospel, flourishes when we believe that deep, pervasive, unending suffering is an imposition into the normal life of relative ease and health.

Our history as a species helps us realize just how untrue the emotional prosperity gospel is. God gave us the first glimpse of the gospel right after Adam and Eve plucked the forbidden fruit from the Tree of the Knowledge of Good and Evil. After explaining the terrible reality of what their new habitat and life would look like—a life that would end with their returning to the dust from which they were made—God promised that one day a descendant from the woman would crush the head of the devil who deceived them (Gen. 3:15). This gospel, this good news, has been around as long as that terrible curse has governed the boundaries of where we live our lives. And while it has been a source of hope and salvation, it has not turned human life into a space free of pervasive trouble.

For most of human history, chronic pain and suffering lurked just around the corner. Have you ever stopped and wondered how many of Abraham's shepherds tore an ACL running down a flighty sheep? Or how many of David's warriors felt the crunch of bone during a routine training exercise gone wrong? Or how many mothers didn't recognize their own bodies after child-birth (if they survived it)? In the expansive ages without surgical interventions, such maladies were permanent with no hope of recovery. The popping of a ligament often sentenced a person to an entirely different life from the one they had known before. One wrong turn on a knee, one fall down a staircase, and nothing would ever be the same.

The Scriptures show us a picture of one such chronic pain sufferer. Little Mephibosheth, the five-year-old son of Prince Jonathan, was snatched up by one of his nurses upon hearing that his father and grandfather, King Saul, had been killed by the Philistines in battle. In the commotion and hurry, Mephibosheth fell from her arms, gravely injuring both of his feet. He never recovered from his injury, living the rest of his days as a cripple.

Chronic pain and illness quickly bring us back to a reality that we tend to forget in our age of much more advanced

medicine. When all is said and done, we are not the masters of our fate or the captains of our souls. Many diseases and conditions of the past have been driven into obscurity by antibiotics and vaccinations and surgery. And yet our modern advances cannot entirely outrun the truths that the Teacher spoke long, long ago. Our default is suffering, "absolute futility," as our bodies wait with groaning for redemption.

It's easy to forget this when so many babies have had holes in their hearts repaired, so many broken vertebrae have been fused, and so many tumors have been removed. Our hearts cry out, "It shouldn't be like this!" But we have to realize that those cries are a longing for Eden, the place where there was no chronic pain or illness, and not a realistic picture of what life on a cursed earth is expected to be like. I am so grateful that some of my friends have been spared a dark descent into the world of chronic pain and illness because of a doctor's knowledge and skill. But they are the exception and not the rule. Throughout our history, more humans haven't recovered than have recovered. And when my heart cries out, "It's not fair!" these words emerge from the emotional prosperity gospel, the gospel that leads me to believe that ease and happiness and tranquility and health are supposed to be my default life experience right now. Yes, God steadies us in the storm. But no, his steadiness does not set everything aright. It's not that time yet.

The emotional prosperity gospel also contributes to some of the terribly unhelpful comments made to sufferers of chronic pain and illness and to their families. Verses taken as promises that are not promises, unsolicited medical advice, trite Christian phrases, unwarranted and unkind assumptions, and countless other well-intended but sorrow-producing things often illustrate how, at least in the world of health, those around us often live in

a different climate than the one we do. The emotional prosperity gospel is able to grow in a climate where deep medical suffering is not the norm, at least not until you reach an age when the body is expected to begin wearing out. People often struggle to understand just how all-encompassing the life disruption caused by chronic pain and illness can be, and that can be incredibly isolating.

Thankfully a real gospel is out there, a gospel that makes the emotional prosperity gospel seem like a cheap trinket. It, after all, is a story of God himself stepping from heaven into this world of absolute futility. He arrives. He shows us his glory. He is crucified. He rises again. He departs to prepare an eternal future place for us. He sends his Spirit to transform us and strengthen us until we go to be with him. The real gospel is not aloof from or ignorant of all the sorrows and pains we experience. It doesn't erase our pain, but it offers strength for weary hands and comfort for grieving hearts. You may have questions about this true gospel, questions that may have emerged only after you have come faceto-face with the destructive power of chronic pain and illness. If so, that's okay. We'll talk more about this in chapter 4. Until then, watch and see how God meets you throughout the next chapters. Your great suffering requires a great hope, and Jesus is the great hope of the world.