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COUNTED WORTHY: A FATHER'S PERSPECTIVE ON THE THEOLOGY OF SUFFERING

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COUNTED WORTHY: A FATHER'S PERSPECTIVE ON THE THEOLOGY OF SUFFERING

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To the glory of God. I am grateful that my Lord Jesus Christ is with me in every moment of every day and I continue to be surprised by his grace in my life and in ministry.

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PREFACE

I want to thank my wife, Mary, the most incredible partner in life and ministry. I love you more than my words could ever express. Your support and unwavering commitment to me and our family, because of your abiding love for Jesus, make you my hero and my very best friend. I want to thank our children, Kathryn, Coleman, Libby, Hannah, and Campbell for their patience in graciously supporting me as I gave myself to writing this work. I am beyond grateful for the ways God uses Kathryn, Coleman, and Campbell to minister to so many through their love and affection for their sisters. These three inspire me with their devotion to God and their care and compassion for those often overlooked. I want to thank Libby and Hannah for being the most incredible instruments of divine grace I have ever known. I am forever grateful that our heavenly Father chose me to be your dad. I want to thank my immediate family for supporting me in the writing of this project, but even more in the unwavering support of our family and unconditional love of our girls.

I want to thank my supervisor and friend, Dr. Chris Kouba, for his support of this project, but more importantly for his friendship in our sometimes challenging life. I want to thank Dan Dumas for his investment in my life and his insistence and encouragement to write this work. I want to thank New Beginnings Baptist Church and Prestonwood Baptist Church for being the hands and feet of Jesus to the Bales family throughout our journey and in the midst of every challenge. I want to thank The Southern Baptist Theological Seminary for the opportunity to participate in this incredible program.

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CHAPTER 1

INTRODUCTION

Where I live in Texas, the weather can change very quickly. It can be sunny and nice outside one minute, and dark and stormy outside in another. Sometimes, those unexpected storms create major problems for drivers trying to navigate the road. In many ways, it has been my own experience that life can work in a similar way sometimes. Most people have ideas, dreams and plans for how they think, pray and hope their life is going to work. But, anyone who has lived much of it already knows that it rarely ends up as it started out. The unexpected storms of life can show up and spin us out, and leave us crashed in the ditch. In our broken world, things do not always work as God originally designed and therefore, most people have spent some portion of their lives trying to get out of the ditch and back on the road to wherever it is they are trying to go.

My wife, Mary, and I have been in the ditch. Our first big storm hit on October 6, 2008, when we had our third child—our daughter, Libby. Libby was born with a very rare chromosomal abnormality called Trisomy 16p. Although she is eleven years old now, Libby has the cognitive development of only nine months of age and severe physical disabilities that render her non-ambulatory and non-verbal as well. Since Libby's birth, we have spun out more than a few times, including at the arrival of Libby's younger sister, Hannah, who despite the "mathematical impossibilities" was diagnosed with the exact same genetic condition and is disabled in the same ways. Our family's struggle through the storms of suffering is why I am writing this thesis. I know that life will spin people out sometimes, and that storms are a part of life. Our family has experienced more than one storm, and judging by the unpredictability of life's weather, we will

probably be hit with a few more before it is all done. Jesus spoke of this reality in Matthew 7:24-27, when He said,

Everyone then who hears these words of mine and does them will be like a wise man who built his house on the rock. And the rain fell, and the floods came, and the winds blew and beat on that house, but it did not fall, because it had been founded on the rock. And everyone who hears these words of mine and does not do them will be like a foolish man who built his house on the sand. And the rain fell, and the floods came, and the winds blew and beat against that house, and it fell, and great was the fall of it.¹

Jesus said the rains fall, the flood waters rise, and the wind blows hard. It is a fact. Bad weather is coming, and storms are in life's forecast. This is a part of life and sometimes that stormy weather will crash someone out or leave that person stranded as they try to navigate the journey of their life. Our family has been in the ditch more than once, and you can bet we will end up spun out a few more times still. However, we are learning how to drive in the weather and perhaps by our transparency others can be better served for their road trips in life as well. The good news for all of us is that God's Word is not silent on the subject of suffering.

My research and thesis concentrate on the need for a deeply empathetic work on suffering to be created and developed that can help sufferers navigate the necessary theology when faced with trial and tragedy. I seek to offer a unique resource for the church, through the personal story of a fellow sufferer, as my family and I have learned how to trust God in the midst of our own hardship. I will share the clear biblical teaching regarding the sovereignty of God in and over suffering, while highlighting personal examples from my family's story of suffering as the proving ground for this truth. This work is aimed to help develop the church in a better and more robust theology of suffering, but as given from the empathetic, raw, and honest perspective of a grieving father. I want to lovingly and honestly challenge sufferers to assess their own conviction regarding how their personal suffering has affected their awareness of the presence of God and their

¹ All Scripture quotations are from the English Standard Version, unless otherwise noted.

disposition toward him. This work is ultimately an encouragement and source of strength for suffering people who might find the authenticity of my family's story a validation of the conviction I seek to share, as founded upon the truth of God's eternal Word.

For this work, I primarily engaged with eighteen different Christian resources on the subject of suffering. These resources varied from biblical commentary to personal story. I gained a tremendous help and appreciation for so much of the work dedicated to helping sufferers navigate suffering through a redemptive lens of faith in practice.

I will briefly review each of the resources that served to help the research of this work and which are referenced within it. I will address these resources by alphabetical order of the author's last name, beginning with *If God Is Good: Faith in the Midst of Suffering and Evil*, by Randy Alcorn.² This book is probably the most quoted within this thesis project. It offered tremendous help in providing a systematic theological framework. Alcorn offers a well-rounded understanding related to the cosmic cause of suffering and the ultimate sovereignty of God over suffering.

Author Jerry Bridges wrote a tremendously helpful book entitled, *Trusting God: Even When Life Hurts*.³ This resource is easy to navigate and the content is manageable, but it does not sacrifice on the theological truth it espouses nor does it lack for personal and pastoral application. I specifically enjoyed chapter 12, which deals with the workmanship of God through the challenges of human suffering. This chapter was considerate to the sufferer and yet faithful to the biblical understanding of God's sovereignty and his grace.

Additionally, the book, *Joy in the Sorrow: How a Thriving Church (and its Pastor) Learned to Suffer Well,* by Matt Chandler was also resourced and studied for its

² Randy Alcorn, *If God Is Good: Faith in the Midst of Suffering and Evil* (Colorado Springs: Multnomah, 2009).

³ Jerry Bridges, *Trusting God: Even When Life Hurts* (Colorado Springs: Nav Press, 2016).

contribution.⁴ In this book, Chandler and members of his church offer personal stories of suffering as a dialog of illustrative examples of God's grace in the midst of great human difficulty. The book includes a balance of scriptural support, which speaks to the presence of God in suffering circumstances along with the conquering work of Christ over the effects of suffering in eternity. Chandler offers a pastoral balance in his opening chapter, along with his own personal story of suffering through brain cancer, as an incredible authority for his convictional arguments. This work was unique in its sampling of suffering from within the context of a local church. This style of shared stories, woven with biblical truth, proved valuable. The practical stories shared, along with the repetitive inclusion of God's Word as the authority for argument, made this resource a great value and one that supported my research well.

D. A. Carson and Kathleen Nielson's *Resurrection Life in a World of Suffering* provides a good narrative commentary on the work of the apostle Peter's epistles, as recorded in the New Testament.⁵ Given the nature of Peter's work, writing to persecuted Gentile Christians of the first century, things could be drawn out of Peter's encouragement to the church that are timeless in serving the sufferer today. This work is limited however, in that it is mostly a textual commentary and resource of Peter's epistle only. The absence of personal story and modern application proved to be a limit on its benefit. Additionally, author D. A. Carson's *How Long, O Lord* is a deep dive into the theological premise and biblical understanding of suffering.⁶ Carson is thorough and honest in dealing with the difficulty of suffering. His work offers a clear and academic dissection of suffering's

⁴ Matt Chandler, *Joy in the Sorrow: How a Thriving Church (and Its Pastor) Learned to Suffer Well* (London: Good Book, 2019).

 $^{^5}$ D. A. Carson and Kathleen Nielson, $\it Resurrection\ Life\ in\ a\ World\ of\ Suffering\ (Wheaton,\ IL:\ Crossway,\ 2018).$

⁶ D. A. Carson, *How Long, O Lord? Reflections on Suffering and Evil*, 2nd ed. (Grand Rapids: Baker, 2006).

cause and effects. This text proved helpful in developing good theological content on the subject of suffering.

Author Elizabeth Elliot has two books which were resourced for this project. First, Suffering Is Never for Nothing, was perhaps the most helpful, albeit somewhat brief personally illustrative work of gaining a theological perspective through personal tragedy.⁷ By using her own life and learning and allowing God's truth from his Word to be laid over that as ultimate in its authority, Elliot offers the reader a tremendously authentic look at the need for a good understanding of God's eternal hope in the midst of life's brokenness and suffering. Second, in *Through Gates of Splendor*, Elliot tells the powerful story of her martyred husband, Jim, who was killed by an Indian tribe deep in the jungles of the Amazon rainforest while he was trying to reach them with the gospel of Jesus Christ.⁸ This book is powerful, in a similar way to her previously referenced work, because of its raw and personal narrative built on deep suffering and tragedy. She gives good scriptural evidence for her developed confidence in the power of God experienced through suffering. This book limits itself in that it does not aim at shaping or sharing an overtly theological framework for how the Christian should see suffering, but it does provide a personal understanding of how she has arrived at her own theological conclusions based upon the power of God's Word and the perspective her own experiences have provided.

Author Dave Furman has a brief, but deeply personal work entitled, *Kiss the Wave: Embracing God in Your Trials*. Furman offers a personal outworking of a deeply theological conviction on the subject of suffering. Using a debilitating nerve condition as his own backdrop of suffering, he offers a personal perspective working in concert with

⁷ Elizabeth Elliot, *Suffering Is Never for Nothing* (Nashville: B & H, 2019).

⁸ Elizabeth Elliot, *Through Gates of Splendor* (Carol Stream, IL: Tyndale, 1996).

⁹ Dave Furman, Kiss the Wave: Embracing God in Your Trials (Wheaton, IL: Crossway, 2018).

good Bible exposition, sound systematic theology, and some helpful personal application, all which afford the reader a well-rounded resource for encouragement in difficulty. This work proved to be a helpful resource for this project and a general guide for a way in which it could be written and developed.

Author Stephanie O. Hubach, who wrote the book, *Same Lake Different Boat: Coming Alongside People Touched by Disability*, offers the most surprisingly helpful and encouraging resource encountered in all of the research done for this project on suffering. ¹⁰ Perhaps it is because Hubach writes as a mother of a child with special needs, a passionate advocate for disability ministry, or as a theologian with a well-developed personal understanding of the goodness of God in the midst of suffering and hardship, but this book is a tremendously helpful work for any reader; one who has similar experiences with suffering and likewise one who does not. By admission, Hubach does not intend to simply share her story as an encouragement of God's faithfulness in their story of suffering alone but instead seeks to give a broader audience to the understanding regarding the nuances of suffering with varying disabilities and how those challenges can be confronted and overcome by the truth and power of the gospel as understood by God's Word.

Pastor and author Dane Ortlund wrote *Gentle and Lowly: The Heart of Christ* for Sinners and Sufferers, which is a great resource on the broad understanding and application of God's grace as made evident through Jesus' life and ministry, as he relates and serves all people in the midst of sin and its consequence, suffering. ¹¹ Ortlund offers the full theological framework for sin as a consequence of the fall of humanity and the subsequent realities of suffering which have resulted since. His biblical faithfulness and thoroughness make the truth he contends for very trustworthy. Additionally, he reveals

¹⁰ Stephanie O. Hubach, *Same Lake Different Boat: Coming Alongside People Touched by Disability* (Phillipsburg, NJ: P & R, 2006).

¹¹ Dane Ortlund, *Gentle and Lowly: The Heart of Christ for Sinners and Sufferers* (Wheaton, IL: Crossway, 2020).

his pastoral heart in offering several stories of personal and ministry application so that the content is processed and applied as the convictional positions are being argued from a solid, biblically faithful place.

Authors John Piper and Justin Taylor dove into the deep end of the theological pool on suffering when they wrote *Suffering and the Sovereignty of God.* ¹² This work was deeply theological and thoroughly biblical. Offering an academically helpful and biblically resourceful look at sovereignty as it relates to the subject of suffering, this book was the most academic and technical of the project research. One could contend that it lacks tenderness and personal connection, but it provides a thorough view of a delicate subject. Using both a systematic and biblical approach, the writers carefully build the theology for suffering in a robust way, leaving little for the reader to lack for understanding about this biblical reality. This book was rich with scholarship, as much as any I studied for my work, but was somewhat cumbersome to navigate simply because of the absence of personal connection.

Noted disability advocate Joni Eareckson Tada co-authored a book with Steven Estes entitled, *When God Weeps: Why Our Sufferings Matter to the Almighty.* ¹³ In this book the writers do a fantastic job explaining the character of God as seen and made known through biblical stories of suffering. This is further illustrated and undergirded with many personal stories of suffering and tragedy. Tada and Estes do a very good job of explaining the sinful human condition and the brokenness of God's creation as the underlying reason for all suffering, but are likewise faithful to share a thoroughly biblical exposition of God's grace in suffering, as most visible through the gospel of Jesus Christ. They offer a life-giving hope as to the totality of God's redemption, including a biblical

¹² John Piper and Justin Taylor, *Suffering and the Sovereignty of God* (Wheaton, IL: Crossway, 2006).

¹³ Joni Eareckson Tada and Steven Estes, *When God Weeps: Why Our Sufferings Matter to the Almighty* (Grand Rapids: Zondervan, 1997).

examination of heaven and eternity with God, where suffering ceases to exist. I found this book to be dense in biblical and academic offering, but helpful and hopeful in both its inclusion of personal story as well as its redemptive arc for the ultimate future of all who are found in Christ and belong to God.

Pastor and author Timothy Keller provides perhaps the second most referenced work in this thesis through his book, *Walking with God through Pain and Suffering*. ¹⁴
This work was incredible; it was deeply theological, tremendously practical, and terribly personal, with a litany of stories from fellow sufferers. The seriousness with which Keller takes the subject of suffering, tragedy, trial, and loss is obvious. He provides a thorough biblical examination, applying a systematic framework for discovering the mercies of God through suffering. Keller's heart and pastoral sensitivity likewise ring throughout the book as well. The book offered a clear gospel explanation and response to the subject of suffering. Keller does not shrink back from the consequences of sin as they plague sufferers both directly and indirectly alike, but he is also tremendously redemptive in his fully biblical review of God's great redemption through the story of humanity rescued in Christ. The book is a robust offering on suffering, and is saturated with solid biblical exegesis that demand the readers consideration. In a way that is similar to only a few others, Keller gives the reader hope with a reminder of how the Bible promises things will end for believers in Jesus Christ.

Authors Larry J. Waters and Roy B. Zuck provided what was perhaps the most academic work on suffering that I used for this project's research in their book, *Why, O God? Suffering and Disability in the Bible and the Church*. ¹⁵ In this book, the writers set out to answer the most natural human question regarding suffering and the sovereignty of

¹⁴ Timothy Keller, *Walking with God through Pain and Suffering* (New York: Penguin Random House, 2013).

¹⁵ Larry J. Waters and Roy B. Zuck, *Why, O God? Suffering and Disability in the Bible and the Church* (Wheaton, IL: Crossway, 2011).

God: why. Using the fervor of biblical scholars, the writers concentrated their work on helping the reader see the nearness of God to sufferers. Beyond the Scriptures, the Waters and Zuck offer church history and the martyrs and sufferers of its past as further evidence of God's provision in and through suffering. I found this book to be a helpful resource in its thoroughness, but difficult to read for application. The absence of personal connection and scarcity of personal stories about suffering kept the writers at a distance and lacking memorable connection with the reader.

Author and biblical counselor David Powlison offers a deeply personal examination of suffering in his book, *God's Grace in Your Suffering*. ¹⁶ In a completely unique way, Powlison uses the words from the classic hymn "How Firm a Foundation," as a creative means to explain a theology of suffering. He weaves Scripture and personal story together throughout the book, in addition to the artistic review of the ancient hymn as the process chosen that helps the reader see the workmanship of God through the challenge of suffering. Powlison's wisdom and experience as a trained biblical counselor can be felt through the tenderness of the work, which made the book easy to digest and given its creative composition, a memorable and helpful way for the subject of suffering to be learned, as the Bible demands that it should and as God's grace. He offers an applicable and personally encouraging work in that he thoughtfully challenges his readers to lean into God in the midst of suffering and to lean into the suffering as well, to learn how God's grace meets people in every challenge which we face.

Joni Eareckson Tada wrote a deeply personal and powerfully theological book entitled *A Place of Healing: Wrestling with the Mysteries of Suffering, Pain, and God's Sovereignty.* ¹⁷ Wrestling with the question of why, Tada offers the reader a close look into her personal struggle with a profound physical disability and the subsequent

¹⁶ David Powlison, *God's Grace in Your Suffering* (Wheaton, IL: Crossway, 2018).

¹⁷ Joni Eareckson Tada, *A Place of Healing: Wrestling with the Mysteries of Suffering, Pain, and God's Sovereignty* (Colorado Springs: David C. Cook, 2010).

discoveries she has uncovered about God, his grace, and the Bible's timeless truth that speak to it. Giving the reader a personal look into her own wrestling with God, Tada acknowledges that she still suffers from chronic pain and is often tempted to wrestle over these questions. Even beyond the question of God's goodness of grace in the initial tragedy of her accident, I found the authenticity of this work a tremendous encouragement and was only surpassed in value by Tada's careful and thorough handling of the Scriptures in answering all of the logical questions anyone would ask who is battling a season of suffering.

Pastor and author Paul David Tripp offered what was arguably the most concise and yet thorough offering on the subject of suffering of all that I encountered in my research. In *Suffering: Gospel Hope When Life Doesn't Make Sense*, Tripp offers the deepest theological truth about God's grace in suffering, but in the most palatable and helpful way so that it became an often referenced and quoted resource for this project. Additionally, using some personal examples and a number of pastoral stories, he provides the reader with illustrative examples of this profound grace in action. Tripp does not shrink back from the reality of humanity's brokenness, nor miss the opportunity to herald the hope that the gospel alone affords all sufferers who place faith in Jesus Christ. He seeks to serve his readers by helping to navigate the challenge of understanding, which is often associated with suffering, especially when it is unexpected and sudden. Using a thoroughly biblical argument, paired with a pastoral empathy, Tripp has given a valuable resource that is easily digestible and biblically faithful.

Finally, the most surprising resource I encountered as a part of my research was *Dark Clouds Deep Mercy: Discovering the Grace of Lament Mark Vroegop.* 19

¹⁸ Paul David Tripp, *Suffering: Gospel Hope When Life Doesn't Make Sense* (Wheaton, IL: Crossway, 2018).

¹⁹ Mark Vroegop, *Dark Clouds Deep Mercy: Discovering the Grace of Lament* (Wheaton, IL: Crossway, 2019).

Wading into waters of biblical lament, Vroegop offers an unbelievable gift in helping readers see the grace of God through the discipline and practice of lamenting. While not offering a significant number of personal stories or illustrative modern examples, he does build a compelling case for the value of sufferers engaging in this practice as a redemptive blessing from God. The book was robust in its theology, sound in its exegetical delineation and rigorous in its effort to assign value to the lost discipline and practice of lament.

Void in the Literature

The primary void in Christian literature, as it relates to the subject of suffering, is one of a combination between personal empathy and biblical truth. A great deal of resources exist that tell powerful personal stories and additionally a number of resources exist that offer deep and theologically sound biblical truth. The combination of those in a palatable, personal narrative is what this project, through the telling of my family's story of suffering, provides.

The need for readers, as fellow sufferers, to feel connected to the author as someone with a powerful personal experience of suffering is tremendously valuable. This point of connection through story offers credibility and value in a unique way. While many resources provide powerful stories to be sure, few offer the parallel of biblical truth and sound theology as the framework which is to be intertwined into the story of personal suffering, offering the reader the greatest help. Likewise, the resources that provide the deepest and most thorough explanations and exegetical emphasis on the biblical theology of suffering are sometimes found to be lacking in human empathy and personal application, which renders those works as helpful intellectually, but not applicable practically.

This thesis provides the church with a resource that combines the power of personal story, including the honest and raw details that grant credibility to the author and for the reader, along with solid exegetical work from Scripture and a subsequent weaving of theological truth throughout.

Thesis Statement

Through the honest sharing of our family's personal story of suffering, having two daughters with severe special needs, and using John 9:1-4 as the primary scriptural backdrop, a biblical case for the theology of suffering is made. God uses suffering for redemptive purposes, both in the life of the sufferers and to advance the mission of the kingdom of God, because suffering is never wasted for a life surrendered to God. Based upon personal experience, biblical exegesis, and interaction with academic literature, this project will conclude with five discoveries every Christ-follower should know as they relate to the reality of human suffering and the sovereignty of God.

Outline of Chapters

This work is an exploration of the theology of suffering based on God's Word and personal experiences. It ultimately seeks to encourage and strengthen fellow sufferers, as well as provide a unique resource for the church to be equipped to minister to those who are suffering. Chapter 2, "The Beginning of Suffering," delves into the personal story of my family, giving a background to our life and faith, calling into ministry, and emotions experienced in the initial stages of suffering through the birth of our two daughters, Libby and Hannah, who have severe physical and cognitive disabilities.

In chapter 3, "Counted Worthy to Suffer," the focus moves beyond the initial shock and confusion to an understanding of the "why" behind personal suffering, and shifts toward gaining clarity of the "what" God is doing through the difficulty of personal suffering. Through the continuation of our family's story, this chapter shows how the sovereignty of God brings supernatural comfort to the sufferer.

Chapter 4, "Completed through Suffering," continues to exploit and explore the redemptive thread of suffering. Using my daughters as the continued testimony, this chapter gives an honest explanation of how God continues to shape our family's theology of suffering, as well as to open doors for ministry opportunity which are desperately needed for others navigating the choppy waters of suffering. The reader is also

thoroughly challenged through self-examination and extended a personal encouragement to either (1) endure well current challenges, (2) reflect appropriately on past challenges, or (3) ready themselves in grace toward the challenges which are sure to come.

Chapter 5, "Conclusions About Suffering for the Broader Church," concludes the conversation about the theology of suffering as experienced through our family's personal story. The project offers five critical elements that have been learned through the study of God's Word and seen applied through the tragedy of personal suffering. This chapter aims to serve the church at large in hopes of equipping her for the difficulty of ministry in the mire of suffering.

CHAPTER 2

THE BEGINNING OF SUFFERING

In the spring of 2018, on a routine Saturday morning, I went into my daughters' room to feed them and change diapers. I suddenly noticed that my six-year-old daughter Hannah, was not breathing well at all. The color was gone from her face and she was making a weak gasp with every attempt to draw her breath. I quickly scooped her into my arms and made sudden arrangements to rush her to the hospital where, upon arrival, the doctors began to administer breathing assistance, while making one failed attempt after another to insert a breathing tube into her lungs. My little girl was dying right before me. While the doctors and nurses worked furiously, I could only stand at the foot of her bed and weep, begging God to spare her life. Hannah had crashed. But that is not where this story begins or how it has ended up. This is our story.

Charmed

Looking back, I would describe my early years as a newlywed and young family as "charmed." I met my wife, Mary, in high school while working at a Christian summer camp in 1994. This was the summer before our senior year of high school and when we met at camp, we quickly became fast friends. While we were both dating other people back in our respective hometowns, we had a strong connection to one another that proved to be binding. After camp ended, we stayed in contact during our senior year of high school by writing letters to one another. Mary lived in Katy, Texas, a suburb just outside of Houston and I lived in Coppell, Texas, a suburb just outside of Dallas. In the busyness of that spring of our senior year, our communication became less frequent, and by the time we were heading off to college for our freshman year, we had lost touch. I spent my freshman year at Southwestern University in Georgetown, Texas, where I

played basketball and Mary attended Texas Tech University in Lubbock. After the frustration of an injury and some serious freshman immaturity, I decided that I would transfer as a sophomore to Texas Tech and study landscape architecture. Early in the fall of 1996, during my first weekend in Lubbock, I ran into Mary again at an event. The connection was instant and beyond exciting, and we began dating in the fall of our sophomore year and fell in love right away.

With the exception of a few months, Mary and I dated throughout our time in college and were engaged on the weekend of her graduation in May of 1999. Following her graduation as a social work major, Mary began working at the University Medical Center as a hospital social worker and served primarily in the ER, burn unit, and post-surgical floor, while I was completing my final year in the landscape architecture program. Our parents were incredibly supportive as we planned our wedding and worked toward life after college, and it seemed that our "charmed" life was beginning to take shape.

Mary and I were married on July 1, 2000 at St. Justin Martyr Catholic Church in Houston. I can say today, having been married twenty years, I am without a doubt more in love with that girl from summer camp than I have ever been before. It is no exaggeration for me to say that apart from my salvation by faith in Jesus Christ, Mary is the greatest gift God has ever given to me and I am overwhelmed by the continued blessing she is to me and to our entire family.

We honeymooned in Lake Tahoe and upon our return rented an apartment in a brand-new complex in Grapevine, Texas, the neighboring suburb to Coppell. I got a good job with a small landscape design/build company in Coppell and likewise, Mary found a job working as a social worker assisting a local school district on the outskirts of the DFW metroplex. We quickly settled ourselves into the comfortable and affluent suburban American life. We found a great local church, made great friendships, and were climbing the ladders of success in our respective careers. We were earning well,

living well, and things seemed to be heading in a smooth and successful direction. We were living a "charmed" life, and it only got better.

We were blessed with our first two children, Kathryn and Coleman, in 2004 and 2006. Both were easy babies and showed me how much joy being a parent could be. During these years of starting our family, Mary and I also started a business. Having earned my degree in landscape architecture and then gaining a good deal of experience working for several small to medium sized landscape companies in and around Dallas, we boldly struck out on our own and formed 3B Landscape Development, Inc., a landscape design, build, and maintenance company. Our family was blessed and fortunate that our company launched with great success and within two years I was given an opportunity to merge 3B with a much larger landscape company in Dallas, where I would earn an equity position as a part owner and would be given the daily responsibilities of General Manager for the entire business. Obviously, this served as an incredible springboard for my career. Becoming part owner of this much larger firm provided us long-term financial security that would have taken many years to earn otherwise. As a couple, while Mary and I were still figuring out parenting and navigating the daily battles of running a business, we were managing well and from our perspective our life was very successful by the measurable "American Christian" standards. That is, for a western Christian who is, by whole world standards, exceedingly blessed financially and medically, with respect to available healthcare and based upon general living conditions, the Bales family was prospering.

Given how good things were going, and knowing we both wanted a large family, we decided to try for a third child. Of course, knowing what I do today, I am convinced that it is God's sovereignty alone which determines how many children a family may or may not be given and by what means. Some families have children naturally and other families are given children supernaturally, through foster care and adoption, and it is by God's grace that all families are formed. The growth of our family

was not always easy. However, after a sad and disappointing miscarriage, Mary became pregnant with our third child, a girl. I could not wait to see how our "charmed" life would take shape next.

Called

After ten years into vocational life in ministry, there are still days when I cannot believe that this is the life God has chosen for me. I love serving the local church as a minister of the gospel of Jesus Christ and I consider myself blessed to serve. I love being a pastor and cannot imagine doing anything else. I love the church where I serve, the staff with whom I serve, and the role that has been entrusted to me to fulfill, but there are times when what I do, as a vocational minister, seems to be the furthest thing from what I thought I would be doing. This ministry life is not how I diagrammed our "charmed" life to be.

My personal story will help give context to the life that Mary and I now live, the faith and strength by which we live it, the vulnerable transparency required for it, and the hope that we have despite all of the challenges that come with it.

My journey of faith began early in my life. My first memories of church or the things of God are vivid. I was fortunate enough to be born into a family with a mom and dad who both loved and worshipped Jesus faithfully. Having grown up in a family of faith, my relationship with and knowledge of God existed from an early age. That said, however, I did not understand the personal reality that a saving relationship with God should entail until much later in my life. I knew about God to be sure, but I did not have a personal relationship with Him.

My parents had my brothers and I in church for all of our lives and did a wonderful job of sharing with us God's goodness, provision, and forgiveness, and our need for his grace. That said, I still grew up with a warped understanding that my relationship with God was as dependent upon my behavior and external actions as it was God's goodness given to me, or at least almost. This mindset led to my young life, most

especially my teen and early college years, being exhaustively given in an attempt to look one way for those whom I thought it mattered to please, while being another way by myself and with others whom I did not think would notice or care. Over time, I grew more calloused to my sinful pattern of double living and less concerned with the opinions and perceptions of others, so long as my sinful desires were being met and my personal pleasures were being satisfied. I was like the man that James describes in his New Testament letter: "He is a double-minded man, unstable in all his ways" (Jas 1:8). That was me, and if I am honest, at times still is—double-minded and unstable. My life went this way throughout high school and for my first few years of college.

The summer before my junior year of college I was invited by a friend to join him in working on a cattle ranch in a small town in Colorado, which seemed like an adventure that few would be able to match. My parents and Mary agreed that this was worth a shot, so in May of 1998, I left for Salida, Colorado, where I began working on the /LD ranch as a summer laborer. The owner of the /LD ranch was a semi-retired businessman from Austin, Texas, who had decided to move to Colorado and pursue his lifelong dream of ranching. In addition to being a cowboy and rancher, he was also a strong Christian who used his ranch and summer employment opportunities to mentor and disciple young, college-age men, in the faith of God he enjoyed.

As summer began, things were going well. Work was hard, but the adventures were exciting. Some days the tasks were mundane and boring, but other days we would drive herds of cattle into the high country on horseback and be gone all day. Those trips were epic and hardly felt like work. We saw deer, elk, and all types of wildlife, all while sitting in the saddle and moving cows through what seemed like a hidden part of God's creation that had never been discovered before. The views were amazing, the weather was perfect, and the other college guys I worked with made the down time fun.

The ranch owner had a structure for getting to know each of us college guys on a personal level. One day a week, each of us would get up early for breakfast and Bible

devotion with him. This was our one-on-one with this cowboy who loved Jesus so much, and it was his opportunity to invest in us personally and individually. Each meeting was an opportunity to share about our faith and to learn from this godly man. Sometimes we would share; other times he would tell us what his take was on a certain passage in the Bible and if necessary, he would challenge us on our beliefs and give us food for our thoughts that day.

On one particular day, it was my turn for early morning devotion. I trudged down to the house from the trailer bunkhouse where we stayed, flopped down at the kitchen table, and prepared for another day of going through the spiritual motions. I was a professional at faking my way through spiritual activities, like Bible study. Being so early, and being so full of myself, I was tired, and I am sure acting in an arrogant way that morning when out of nowhere this ranch owner called me out. We were reading something in the Psalms, I still cannot remember what, and I am sure after giving some meaningless response to his question about what we were reading, this old cowboy went off on me. I do not remember everything he said verbatim, but the gist of it was this, "Connor, you're a primadonna! [that word I absolutely remember]. You're a jock who has always had a great deal of life handed to you on a silver platter. You're spoiled and I think you're a fake in regard to what you say you believe." He concluded with, "Son, I think you had better do some soul searching to find out if you're even a Christian and saved "

What? I was furious! I quickly finished breakfast and started my workday early. On this particular day, I had been given the task of spraying wild irises with an herbicide. I considered this the worst task on the ranch for a couple of reasons. First, this was a job done alone. The sprayer missed all of the fun of socializing and hanging out with the other guys on the ranch, which made the day go so much faster and made the work so much easier. Second, the sprayer did this work using a backpack sprayer and filled it with not only the water and chemical needed to kill the plants, but with a blue dye

so that it was apparent what had been sprayed and what had not.¹ Finally, I hated this job mostly because the backpack sprayer leaked. So, after a long, boring, isolated day of spraying plants in a pasture alone, the sprayer would go home to a back and backside stained with blue dye. Since it was a commercial dye, it would not come off in just one or two showers either. Miserable.

On this day however, since it was a solo job and I was left out there all day with just my thoughts, and they were not good thoughts it turned out, I now know by God's grace it had been the perfect job for me. I stewed for what seemed like hours. I kept thinking, "How dare he challenge me and question my faith? Doesn't this guy know I was raised in a Christian home? I've been in church my whole life. I grew up in our church youth group. For the most part, I'm a good guy, and no one, certainly not this old man, knows about my secret sins!"

However, the funny thing is, he did not need to know about them. My double-minded life had led to an instability that I could not see. This cowboy knew I was "faking it" spiritually and by God's grace he had the courage to call me on it. Looking back on that experience today, I am grateful for that cowboy's courage and boldness and after a few hours of wrestling, I surrendered. On July 29, 1998, I prayed in the middle of that pasture and asked God to save me. Right then, right there, God saved me, and my life was transformed by His grace. Of course, while I am still a redemptive work in progress, I have not been the same since that day.

Unfortunately, after my salvation I was not really discipled in my newfound faith, so I stayed in the shallow end of the gospel pool for several years. I still struggled with some of that old besetting behavior, but being saved meant I now had God's Holy Spirit living within me to help guide me in my daily fight. The process was and is slow,

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¹ If you are wondering why spraying wild irises would even be a job needed at a working cattle ranch, you are not alone. Essentially, while boring to do, this work was necessary so that invasive irises would not overtake the pastures, ruining the native grasses and rendering the pasture as useless for the much-needed grazing ground.

but I began making gains and Jesus was slowly but surely becoming more and more the center of my life and the foundation upon which I lived it. I knew what it meant to struggle; I had known that my whole life, but now, in Christ, I knew what it meant to struggle well. I began to live my life empowered by God's Spirit and to battle sin with integrity and hope. I was not made better; I had been made new. I knew what Paul meant when he wrote 2 Corinthians 5:17: "Therefore, if anyone is in Christ, he is a new creation. The old has passed away; behold, the new has come." Today, I can say confidently that while I am not yet who I want to be, I am no longer who I was either. I am, by God's grace, saved!

Author Stephanie Hubach explains the gospel of Christ and the salvation of God in a way that I have grown to appreciate more and more over these years since my conversion that summer day. She writes, "The beauty of the gospel, if we truly understand it, is that each of us faces a complete barrier to participation in the kingdom of God due to the profoundly disabled condition of our hearts. The good news is that Christ's perfect sacrifice applied to us makes our full participation in the life of God a reality."²

After college and as a newlywed couple, Mary and I knew we needed to find a church to call home. Fortunately, we found my home church from high school as the right fit for us to start. We quickly settled in and made friends with other young couples. We found a great small group in our Sunday school class of other young marrieds, and our teachers, who were our parent's age, proved to be incredibly godly mentors in our life. This was a truly sweet season for us as a couple. We grew closer to Jesus, and Jesus grew us closer to one another.

In our church, my high school student pastor was still serving there at that time and after a year of our attending, he asked me to lead the 8th grade boys in Bible study. I reluctantly said yes and within a few months fell in love with those guys and the ministry

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² Stephanie O. Hubach, *Same Lake Different Boat: Coming Alongside People Touched by Disability* (Phillipsburg, NJ: P & R, 2006), 47.

we were having together. After getting them through that year, and before beginning their freshman year of high school, the girls of the same grade were now in need of a teacher and I convinced Mary to join me. Together, we took that group of students from their freshman year through their graduation. It was a great time of fun, and deep spiritual growth for both Mary and me. It is a funny thing that as the teacher begins to study and work to teach God's Word to others, God has a gracious way of teaching His Word to the teacher. This was certainly the case for me. I was growing in my faith faster than any other time in my life and I was falling more in love with Jesus and his church.

During this season, the student pastor left the church and the weekly responsibilities to lead the student ministry fell to Mary and me as the short-term solution of sorts. We worked to plan the Wednesday night worship gatherings as well as the Sunday morning Bible studies and any student ministry events that came each semester as well. On one Wednesday night, we invited a guest speaker to come and minister to the students and while sitting in the crowd and listening to what he said, I heard God speak to me in what was at the time, the most clearly I had ever heard his voice before. God said, "Connor, sell your business because I've called you to this." Well, as you might expect, I responded as every mature Christian should and I panicked. I did not tell Mary anything and worked diligently to convince myself that I was making the whole thing up and I had not actually heard what I thought.

On Sunday of that same week, the pastor preached his sermon and to this day I am convinced he was speaking only to me. The Holy Spirit was all over me and he was asking, "Are you going to say something about what I've told you or not?" As we headed home from church, with our three-year-old and six-month-old in their car seats, I looked over and told Mary with tears streaming down my face, "I think God is calling me into the ministry." Mary's first response was, "Maybe you're just supposed to volunteer more." I kind of hoped at that time that she was right, but very quickly, as the calling God gave me and the feeling he instilled in me only grew stronger, Mary agreed. In fact,

Mary jumped on board with this left turn in our "charmed" life right away. She was not surprised by this revelation and from the moment God made this calling clear, I have always had her full support.

Within a few weeks of this radical calling, I met with our pastor who affirmed God's Word to me and shared Mary's view that this shift was not a surprise to him. My family likewise shared the opinion that they had seen God's growth of me over the last several years and could see the shape of ministry being formed in my life. So, I surrendered. God called this landscape business owner to pursue vocational ministry, by serving his church. I was not sure what that meant, but I was convinced it was what I was supposed to do.

Not long after this calling and conviction came, I was driving around Dallas between sales appointments and job inspections for my landscape company and was listening to a popular radio program hosted by Dave Ramsey, the financial wizard who helps hundreds of thousands of families get out of debt and enjoy financial freedom.

Since one left turn (my calling into the ministry) was not enough, I again heard God, although admittedly not in the audible way I felt that I had before, tell me that our family was to sell our big home and pay off all our debt. When I shared this news with Mary, the shock was not as severe. After all, this made sense practically as we knew there would likely be a significant shift in our income when we started our first ministry position, whatever and whenever that would come. Additionally, we knew we could use the excess cashflow to assist in paying for seminary if I were to pursue the education that would accompany my calling.

As it turned out, the debt free move was the right one. We certainly needed to free up money for changes in our family's expenses, and it was for a new ministry that God would entrust only to us. However, I was not the ministry I expected; in fact, it is a life and a ministry so much bigger than that.

Changed

Once Mary and I sold our home and paid off debt, we moved into an apartment with our two small children (Kathryn and Coleman) and began restructuring our budget to save as much as possible. We began setting money aside to make a down payment on a smaller, more affordable home, in preparation for what we knew would be a change in income that accompanied the change in vocation.

This was a sweet season for us. Mary and I have commented to one another many times since then, that with the simplicity of our life and being obedient to what He had called us to do, it was a great time for our young family to grow. We were flourishing, in all of the ways that matter: spiritually, personally, relationally, emotionally. Of course, as stated, God was preparing us for ministry. It just was not the ministry we had thought.

Mary and I knew we wanted to have a large family. So, by God's grace, we got pregnant and were expecting our third child, a little girl. Mary was due in November 2008, and we quickly settled on the name Elizabeth Faye Bales, but decided that we would always call her "Libby" for short. Mary's pregnancy was perfect. She had no complications, and like prior pregnancies, things moved along without any surprises or concerns along the way.

October 6, 2008 was a Monday. Mary was about five weeks away from her due date, something she had met with each of our two children before. I remember the morning perfectly. I had hung around the house a little later that day because Mary was trying to get things together and was making final preparations for Libby's nursery. We had stored a few things (bassinet, baby bouncy chair, play saucer) in the attic, and Mary wanted me to get them down for her to clean up and make ready for Libby's arrival in a few weeks. While I was in the attic, Mary came to the bottom of the stairs to tell me she was not feeling right and she thought she might be starting labor. I tried to keep calm, reminding her it was too early for labor, and I casually dismissed her concerns by chalking it up to Braxton-Hicks, false contractions. In an abundance of caution, we agreed she should call the doctor and let him make the determination on next steps that day.

Mary's doctor insisted she stop by his office for a quick check, so I adjusted my schedule that morning and we went in for Mary to be seen, with the assumption that we would be sent home. The doctor informed us after a few minutes that Mary was in fact in labor and we went directly from his office to the labor and delivery floor of the hospital next door. At 5:25 p.m. our daughter, Libby, burst onto the scene, weighing 6 lbs. 2oz. She had bleached white blonde hair, an absolute toe-head. Other than the unusually blonde hair, the only thing that physically stuck out to me and Mary at Libby's birth were that both her feet were severely malformed, in that they were pointing straight out to the side and straight up, almost touching the sides of her little legs. They were "funky feet," as we would learn to call them. The doctor, however, noticing our faces of concern and hearing our repeated questions about her feet, explained the anomaly as possibly the result of positioning in the womb and assured us that we should not be worried, and that we would know a lot more in the days ahead.

But, we were worried. Normally, at least with our older two children, after Mary had given birth the doctors would deliver the baby, hand the baby to nursing staff in the room who would clean the baby and immediately check for obvious concerns, and then quickly hand the baby right back to Mary for some precious bonding time together. With Libby, the doctor delivered her, and the nurses began checking her and cleaning her. After a few minutes, more and more staff began to enter the room and ultimately, they just took her away. We were confused. Something was obviously wrong, but no one was saying anything except mostly to one another as it related to working on Libby. All Mary and I knew was that they never gave Libby back.

The doctor continued to tend to Mary, while a nurse informed me that Libby was not breathing as well as they wanted so they took her to the Neonatal Intensive Care Unit (NICU) to could give her more attention, and if needed, supplement her oxygen to help her get caught up. The explanation did not sound too bad and the nurse did not seem that alarmed, so I stayed with Mary and began making phone calls to let family and

friends know that Libby had shown up early. After a few hours, a neonatologist came by our room to let us know that Libby was stable, and that I was welcome to come down and see her, but that they had detected a heart murmur and tomorrow, a pediatric cardiologist would be coming to the hospital to examine Libby and they would conduct an echocardiogram to try and determine the reason for the murmur so a diagnosis could be given.

We thanked the doctor for his time and attention to our little girl and told him we would be anxiously awaiting tomorrow's appointment with the cardiologist to find out exactly what was wrong. Mary and I then together went down to the NICU to see our Libby, to touch her, love on her and to meet those incredible nurses who would be tending to her so closely. After spending some much needed time with Libby, we headed back to our room so that Mary could rest, but honestly, because of the surprise of Libby's early arrival, the complications of her delivery, the news of the heart murmur, and tomorrow's pending appointment, neither of us slept much that night. We were obviously excited about Libby's arrival, but we were also concerned about what little we already knew that was not quite right as well.

The next day we met with the pediatric cardiologist who examined Libby and we were informed that Libby had a fairly severe congenital heart defect called Tetralogy of Fallot. Essentially, this particular defect has four parts of the heart which are affected by the abnormality. It is unusual, but not entirely uncommon, and fortunately the doctor told us that with the advancements of medicine and surgical procedures, Libby's defect could be surgically repaired and that we should expect a first surgery to be sometime around her first birthday. Writing about this today, eleven years later, I recognize what a blessing it is to have modern medicine that allows my daughter's heart defect to be surgically repaired, but then, on that day, I was crushed knowing that she would require any surgery at all. In an instant, it seemed like everything changed.

Libby stayed in the NICU for eleven days. Mary and I went to see her twice every day. Mary was trying to provide milk for the nurses to feed Libby and we wanted to spend as much time with her as we could. Libby grew stronger, more stable, and once she gained enough weight that we could be cleared to load her safely into a baby carrier, we were sent home to begin our new life with this fragile little girl.

On the way home from the hospital, the day of Libby's discharge, we went directly to our pediatrician's office for Libby's first visit. We spent a long time with our doctors. Although we did not know them well, they proved to be an unbelievable gift from God to our family. They are an incredible husband and wife team who took such good care of us for so many years. So, on that day, they got up to speed on Libby's heart condition, heard our plan regarding her feet being fixed, and then they told us what regular well checks and weight checks needed to look like going forward. This then began for us a "new normal" of sorts. Libby began seeing a pediatric cardiologist every week for heart checks and our pediatricians every week for weight checks, and they communicated between their offices to make sure that progress was being made where it needed to be and that conditions were not worsening at the same time. Things had certainly changed for us.

In one of our first visits with the cardiologist in his office, he told us that Libby's defective valve was leaking quite a bit and surgery might not be at a year, but perhaps closer to nine months. Within a week or two after that, he said six months was more likely when she would need surgery. Only a week or two later, he informed us that the leak was continuing to worsen and changed her surgery date to three months and at the next appointment we scheduled the surgery for Monday, December 15, 2008.

I will never forget that day. I got up early with Kathryn and Coleman and took them for Krispy Kreme donuts as a treat that morning before Mary and I had to have Libby at the hospital for pre-op. I knew we would not see the older kids much in the days ahead and I wanted to have some time to spoil them before the chaos began. I remember

that I was so nervous. I ate one donut and threw that up in the parking lot immediately after buckling the kids into their car seats. Mary was a lot tougher than me, at least on the outside. We took Libby in that day and after leaving her with the anesthesiologist and heading into the surgical waiting room, which by God's grace again, was filled with family and friends, we endured what was one of the longest days of our lives. Mary, as it turns out, clinches her jaw when she is nervous and upset. She developed ulcers in the mouth days after Libby's surgery was complete. I do not hide my nerves as well, so I spent about every hour or two crying and vomiting in the men's room for most of that day. We were the picture of stability, let me tell you; and we were a long way from the "charmed" life that I had dreamt of so many years before. However, yet again, God's grace was overwhelmingly good to us, as Libby's heart repair was a complete success and she recovered more quickly post-operatively than the doctors had even expected. We were thrilled.

In a seemingly insignificant conversation with us one day, while she was still recovering from surgery in the hospital, one doctor recommended that Libby have labs drawn to check for any genetic abnormalities, as some are linked to her particular heart condition and we certainly had enough reason for the tests to be run. This seemed like an excellent idea to us, after all, I knew that once we had her heart repaired and could get her feet in some braces to get those fixed as well, it would be smooth sailing for our girl and our family could get back to our version of normal.

In early January 2009, a geneticist called us to let us know that the results of Libby's genetics testing had returned and that she would like to meet with us to go over the findings. Instinctively, Mary and I both knew that meant they had found something, but given our lack of knowledge regarding anything related to genetics, and given our confidence that we had already hurdled the largest obstacle in Libby's life with a successful heart surgery, we headed into this appointment without knowing what to expect. On Thursday, January 15, 2009 our geneticist informed us that Libby had an extremely rare

genetic abnormality called Trisomy 16p. Specifically, Libby was born with a partial translocation of her 16th chromosome.

This particular genetic abnormality is rare because, as our geneticist told us, it is "incompatible with life." We were told that Libby's particular anomaly was only known to have been found in about thirty other people at that time.³ I remember asking the doctor, "Is this like Downs Syndrome?," which was literally the only thing I knew in my limited understanding of genetic defects. The doctor simply responded, "Oh Mr. Bales, this is so much more severe. I would tell you that if you hadn't already had your daughter's heart repaired, I might have counseled you against it."

So, as one might imagine, trying to soak in this news, Mary and I were undone. Everything had changed yet again. We were wrecked. Devasted does not begin to describe our feelings. One of the last things the doctor told us was, "Fifty percent of children born with a genetic abnormality this severe die in their infancy. Libby would most likely not live to see her second birthday, and that we should go home and make her comfortable and enjoy what little time we have left." This news was soul-crushing. Our daughter was diagnosed with very severe, life threatening, life altering, special needs. I still get emotional thinking about that day. I can remember the doctor's office, the colors on the wall, and the furniture where we sat. I can remember the medical book the doctor showed us with the one picture of a young man with Trisomy 16 and the one page dedicated to Libby's condition.

Author and special needs parent Stephanie Hubach shares this reality for a mom and dad perfectly when she writes,

Parents whose child has been diagnosed with a disability experience the sense of a *loss of expectations*—and the associated grief that comes with having a child who is

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³ Naturally, a curiosity seeker reading is going to try and Google this diagnosis of Trisomy 16p and there is a chance you will find something, but not much. Because there is not much. It is rare. Certainly, there must be more cases of this particular genetic abnormality, but most are likely untested or those who have it do not live long enough to be tested, and therefore they go undiagnosed. So, the rarity of Libby's condition is extreme.

markedly different from the one whom they had anticipated. This does not imply that the parents won't love the child who *has* entered their lives. Indeed, they may eventually find their capacity to love expanded beyond their wildest expectations. However, there will be a significant grief that needs to be experienced even as they attempt to fully embrace the child who has arrived. Over the years, this sense of loss will often be revisited when typical milestones in a child's life are encountered under altered circumstances for *this* child. These milestones may include birthdays, graduations, going off to college and other rites of passage.⁴

I did not understand. I did not have a category for Libby's diagnosis. My hurt was so deep and my sadness so real that my chest ached. I remember leaving the doctor's office and heading back to work to gather my things so that I could meet Mary back at home. And, to my shame to this day, I let Mary and Libby ride home after that appointment alone. When we got home, we hugged and cried and cried and cried. We called our families, and I will never forget that both of my brothers, Jayson and Neil, immediately rushed over to the house that afternoon to spend time with us and make sure we were okay. But, we were not. I was numb. Mary was numb. This diagnosis of devastation felt like it was too much for us to bear. Life had changed for us. We were changed.

Confused

I mentioned in the introduction that, being a Texan, I am used to strange weather. In fact, the disparity in weather across the expanse of the state is something that is almost celebrated, in an unusual way. Although it is not limited to Texas, I am always struck by the limiting way that foggy weather can affect a person's routine simply by hindering vision and creating confusion as it is being navigated. When we received Libby's diagnosis, it felt like a dense fog settled into my mind. As it related to Libby's challenges, the only thing I had any certainty about was that Mary and I were going to love her with everything we had and that we would do anything and everything in our power to give her the best life with every opportunity we could afford. Other than that, I was foggy. I was not thinking clearly, I was not praying clearly, I was not leading clearly, I probably

⁴ Stephanie O. Hubach, *Same Lake Different Boat: Coming alongside People Touched by Disability* (Phillipsburg, NJ: P & R, 2006), 85, emphasis original.

was not even loving clearly. With all of the emotions we faced, a dense fog had set in on us and it was affecting how we navigated life.

In the days and weeks after Libby's diagnosis, Mary and I began to digest our new reality. In the mental processing, a wide range of emotions flooded us. We felt shocked, saddened, angry, disappointed, hurt, disgusted, terrified, and broken-hearted, just to name a few emotions. Perhaps the emotion or feeling that surprised me the most, and hung around me what felt like all of the time, is that of confusion. I would like to say that because of my relationship with God through Jesus, and the blessing I enjoyed of God's Holy Spirit alive inside me, that I handled all of these emotions with incredible maturity and spiritual integrity that is worthy of a New Testament story. That, however, would not be true. Not even close.

Because of the fog of my emotions, I could not reconcile in my mind the "why" behind the "what" in Libby's diagnosis and our family's story. Perhaps because of my linear pattern of thinking, I truly did not understand how God could let this happen to my daughter. I was thoroughly perplexed, my confusion led to more frustration, that frustration led to greater confusion, and the cycle was getting worse. I felt like a road warrior who has set out on a journey, only to be limited to a stop or a slow crawl because a dense fog hindered him from knowing the direction to go and what he should be looking for all along the way.

I kept hoping the fog would burn off, like it does most often when it is a part of an early morning weather pattern here in Texas. Mary and I attempted to settle into our new rhythm in our life with Libby, which included a steady stream of doctor's appointments and therapies, a substantial regimen of medicines, the consistency of insurance battles, and thousands and thousands of dollars spent trying to find the best care for our little girl. It was (and is) exhausting and I do not know that I had the depth, maturity, or wisdom to process this new life and all of these new experiences that created these new emotions very well at all. In hindsight, I now know that my struggle, my

confusion, my fog, was essentially my wrestling with the sovereignty and goodness of God. I will explain more of what I have discovered later, but my confusion was quite simply my lack of understanding in the cause and effect nature of life in our broken world. After all, so much of my life was "charmed." I had not had to truly reconcile much in the way of brokenness until life with Libby forced that reality upon us in the most serious ways.

Paul Tripp summarizes the root of my confusion and frustration when he writes, "Your suffering is more powerfully shaped by what's in your heart than by what's in your body or in the world around you." In other words, the external pressure of my life and our circumstances simply served to reveal an internal problem rooted within me. Tripp goes on to say,

Your responses to the situations in your life, whether physical, relational, or circumstantial, are always more determined by what is inside you (your heart) than by the things you are facing. This is why people have dramatically different responses to the same situations of difficulty. This is why the writer of Proverbs says: "Keep your heart with all vigilance, for from it flow the springs of life." (Proverbs 4:23).⁶

I was confused and I did not understand the *why* behind the *what*. I could not personally make sense of what I believed was the senseless nature of our suffering.

I take comfort knowing that I am not alone in my lack of understanding in the cause and effect nature of our broken world. In fact, I have discovered a prominent story recorded in the Bible in which the disciples of Jesus were attempting to reconcile the exact same thing. In this particular story, the disciples do not have the personal relationship with the person experiencing the unexplained suffering, like Mary and I do with Libby, but their confusion as to the cause and effect surrounding it is the same as ours. John 9:1-2 says, "As he passed by, he saw a man blind from birth. And his disciples asked him,

⁵ Paul David Tripp, *Suffering: Gospel Hope When Life Doesn't Make Sense* (Wheaton, IL: Crossway, 2018), 31.

⁶ Tripp, Suffering, 31.

"Rabbi, who sinned, this man or his parents, that he was born blind?" To me, it seems reasonable for the disciples to question the cause for this man's blindness, especially since the passage includes that this particular man had suffered his condition of blindness from birth. So that left a difficult cause and effect question in the disciples mind as they (like me) attempted to reconcile the "why" behind this "what."

If this man had lost his vision after suffering a tragic accident at work, or if his blindness had been the understandable result of a disease he had suffered from as a child, then logically there would be a reasonable, explainable cause that yielded this effect of blindness. However, this man was born blind. Like Libby, nothing seemed to cause this suffering. Mary had nothing unusual about her pregnancy and there were no accidents while Libby was in utero. Likewise, other than showing up a little earlier than expected, there were no complications with Libby's delivery. The disciples seemed confused from the absence of no discernable explanation for the suffering in the story of the man born blind in John 9. In a very similar way, I too was confused.

Theologically, the question of cause and effect in this Bible story is an understandable one for the disciples to have. These men were average first-century Jews whose very world had been turned upside down by the life and teaching of Jesus. For them, the idea of pain, suffering, and evil were explained away by associating those things as consequences of sin.⁷ New Testament scholar George Beasley-Murray offers historical insight when he writes,

The man's plight provoked the disciples into asking Jesus the reason for it. It was widely held that suffering, and especially such a disaster as blindness, was due to sin. The general principle was laid down by R. Ammi: "There is no death without sin, and there is no suffering without iniquity." The disciples evidently accepted this, but in the present case were perplexed as to the application of the dogma. There were grave difficulties in seeing how a man could have sinned before his birth. And

⁷ George R. Beasley-Murray, *John*, Word Biblical Commentary, vol. 36 (Dallas: Word, 1999), 154.

it is not much easier to think that a man should bear such a terrible punishment for the sin of his parents. So the disciples put the matter to Jesus.⁸

In other words, if someone were suffering from an ailment, dire circumstance, or severe problem, the reasons would have been understood as having something to do with that person's failures, or the failures of their parents. Author J. Ramsey Michaels shares,

The notion that a person could be held accountable for his own sins prior to birth is less widely attested and therefore more problematic. Possibly it arises not so much from a particular theological belief as simply an intuitive feeling that because God is just, human sinfulness must somehow lie at the root of all human misfortune. The default assumption was that the victim was to blame, but in the case of someone born blind, the added possibility existed that it might be the parents. 9

The disciples naturally linked sin and suffering together, as did most Palestinian Jews of their day. In one sense, they are absolutely correct to do so, but not in this particular case.

The teaching of the Bible, which those Jewish boys knew at that time and that Christians still know today, is that God perfectly created the world and everything in it, the Bible says it was "very good" (Gen 1:31). It was perfect as God had designed it. It was a created world without sin and therefore without the consequences of sin, which would most certainly include suffering. However, because of the rebellion of the first parents, Adam and Eve, all humanity has subsequently suffered the consequences of sin's fracturing all that God had made as good. The result is that this world is broken and the people that live in this world are broken. While sometimes the brokenness shows up in the creation through natural disasters or in the created through acts of evil and terror, it also shows up on the creation through illness and human suffering. Sometimes it is blindness from birth, or it could be Trisomy 16p. The problem in this story is that the disciples were trying to connect the sin condition of the entire human race with the specific suffering of this individual born blind. They cannot reconcile who is to blame or

⁸ Leon Morris, *The Gospel according to John*, The New International Commentary on the New Testament (Grand Rapids: Wm. B. Eerdsman, 1995), 424-25.

⁹ J. Ramsey Michaels, *The Gospel of John*, The New International Commentary on the Old and New Testament (Grand Rapids: William B. Eerdsmans, 2010), 541.

what is the cause, which rendered this effect. If I am being honest, this is something I can closely relate to myself.

My questions were, "God, why *my* daughter? She is innocent. Have you not seen what she is going through? She is suffering. Look at what has been done to her little body already. Look at the medicines she is constantly having to take. Look ahead toward the future she is being told she will not have. God, why our family? We are doing the right things and trying to follow you. We are being generous with our money and our time and we are faithfully serving your church." And although I am embarrassed to say it now, I even thought, "God, I'm in seminary! I have surrendered my life to a calling into the ministry." I was literally giving God a resume of reasons why the cause of Libby's suffering did not match the effect. I was confused, I was foggy, and could not get the weather to break.

I could not understand the reason for Libby's suffering. I was confused and I was also angry. My self-righteousness mixed with my fear mixed with my grief was the perfect cocktail for this theological and personal conundrum, which I could not reconcile in my mind. I remember thinking very clearly that I could bear it if this suffering were mine. I am a big boy, a tough guy. I can wrap my mind around my own hardship, but I could not understand it being her. My little Libby was innocent. She had done nothing to deserve what it was she was dealing with, and yet I was watching her suffer very seriously. I could not reconcile the cause and effect of this, and it wrecked me.

Tragically, this flawed theology has crept into the western church. I believe what I was feeling and expressing, many fellow sufferers feel and think as well. It reveals evidence that a selfish understanding of how God uses suffering and a short-sided view of grace has permeated a great deal of Christian theology. My experiences have led me to believe that some Christians espouse a view of suffering as either an absence of faith for

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¹⁰ Judith Acosta, "Be Happy or Else: The American Refusal to Deal with Suffering," *HuffPost*, November 17, 2011, https://www.huffpost.com/entry/be-happy-or-else-the-amer-b-815764.

it not being temporarily overcome, or the presence of sin for its existence in the first place. Both of these beliefs are false and are damaging to the nature of God's grace, the power of God's provision, and the supernatural providence of his workmanship in all things. However, some of the initial counsel we received after Libby's diagnosis and some of the conviction I have encountered as a pastor ministering to people in their own trials and suffering have revealed that this predominantly western Christian theology still exists and plagues the church today.¹¹

Tripp summarizes my struggle personally when he writes,

Because our complaints are rooted not just in horizontal dissatisfaction (with people and situations), but also in vertical disappointment (with God), discouragement has the potential to become spiritually debilitating. We don't sufficiently consider the effect that complaint has on us and the way we think about and respond to our relationship with God.¹²

The disciples must have been wondering the same things. The disciples needed some clarity from Jesus as to the "why" of this man born blind that led to his "what." I do not think they were wrecked by the condition of this blind man, like I was about Libby, but they were curious and likely empathetic, given the ministry mindedness they most certainly had learned from Jesus by this point. They are trying to work out one of those ideas that I spoke about earlier of cause and effect. It appears that up until that point, the disciples, and perhaps most everyone else in that culture, had assumed that human suffering was a consequence of personal or familial sin, and in that assumption, they tried to explain away the unexplainable. Likewise, everyone has similarly tried to understand the reason for suffering. Scholar Gary Burge acknowledges the struggle of the disciples when he writes,

Human beings generally seek answers or a rationale that can help them deal with the hard questions of pain, suffering, and evil. Like most confused human beings, the disciples assumed that the problem would be more tolerable if they could probe the

¹¹ Loren Skinkey, "God and Suffering," December 10, 2019, https://www.abwe.org/blog/god-and-suffering.

¹² Tripp, Suffering, 125.

questions of why. Accordingly, they sought to assign blame for the man's unhappy state in life. 13

I have already admitted that I have personally wrestled with the sovereignty of God and the goodness of God, *both* being possible through suffering. I attempted to offer a litany of reasons why it made no sense for Libby to be suffering as she was, and for the Bales family to be enduring the hardship that came along with it. And that questioning, brought on by the fog of emotion, is what is going on in John's account. In this passage, the reader can see clearly the dilemma that many people have thought or wondered aloud, which the disciples boldly voiced. The disciples sought an explanation as to what unmerited human suffering could be attributed to, at its origin. I understand why they asked, and I appreciate the vulnerability that it must have taken for them to acknowledge the need to learn here.

In *Why O' God?*, authors Larry Waters and Roy Zuck build on the dilemma the disciples were facing when they write,

This thought has crossed our minds many times. What did we do? Is there some sin we have not confessed? Is there something God is punishing us for? We have searched our hearts. Jesus's answer is comforting. "It was not that this man sinned, or his parents, but that the works of God might be displayed in him" (v. 3) Sometimes we sound like Job asking the questions God never intends to answer this side of heaven. But we are thankful that while we may not have the answers, he does give us a purpose. His glory.¹⁴

Many that are suffering right now are attempting to navigate a journey of pain or disappointment or failure, only to be stranded by the dense fog of confusion, hindering any rational ability to navigate the journey at hand. It probably feels like the fog is so thick that it is impossible to see down the road. Maybe, similar to me and the disciples, these sufferers have also questioned the "why" behind the "what." In this thesis, I do not attempt to try and explain away emotions as these naturally accompany suffering and

¹³ Gerald L. Borchert, *John 1-11*, The New American Commentary, vol. 25A (Nashville: Broadman & Holman, 1996), 312.

¹⁴ Larry J. Waters and Roy B. Zuck, *Why, O God? Suffering and Disability in the Bible and the Church* (Wheaton, IL: Crossway, 2011), 83, emphasis original.

hardship, and emotions are often a necessary part of the process for navigating a healthy way forward. I would, however, be remiss if I did not remind these sufferers of what the Bible makes clear. God gave emotions, and therefore He can handle the sharing of these emotions with Him.

Randy Alcorn encourages honesty with God as he reminds the reader of Job's story of suffering:

The Bible models honesty with God concerning the problem of evil and suffering. Job candidly expressed his doubts as he questioned God about his suffering: "I will not keep silent; I will speak out in the anguish of my spirit, I will complain in the bitterness of my soul. . . . I despise my life. . . . If I have sinned, what have I done to you, O watcher of men? Why have you made me your target? Have I become a burden to you? (Job 7:11, 16, 20). Just as God knew exactly how Job felt before he said a word, so God knows how you feel and what you're thinking. You can't hide it, so don't bother trying. When you pretend you don't feel hurt or angry or devastated, you're not fooling God. Be honest! Naomi cried, "The Almighty has made my life very bitter (Ruth 1:20). David asked God, "Why have you forsaken me?" (Psalm 22:1). Jesus repeated the same question on the cross. Don't misunderstand; I am *not* encouraging you to be angry at God or to blame him. He deserves no blame. Rather, I am encouraging you to honestly confess to God your feelings of hurt, resentment, and anger. ¹⁵

Honesty with God is the best way forward. He is the safest outlet and audience for His people. In fact, I would plead with the sufferer to process all emotions with God. Share the emotions of anger, sadness, broken-heartedness, grief, frustration, fear, and confusion. He can handle it, and even more than that, He wants to share in the suffering of His children.

In *God's Grace in Your Suffering*, author David Powlison talks about the subject of honest with God:

Seek the Lord honestly. In turning toward him, you will likely be turning away from instinctive and habitual sins. Anxiety? Anger? Despair? Escapism? He is merciful. He "opposes the proud but gives grace to the humble" (James 4:6). Don't be afraid to tell the Lord the truth about your sufferings, your sins, your desires for mercy, your struggles. Dozens of psalms have walked that road. Ask your Father to give you his Holy Spirit. All wisdom, trust, peace, courage, love, endurance, and hope are the fruit of his personal touch. Honest wrestling is not magic. It's not "claiming

¹⁵ Randy Alcorn, *If God Is Good: Faith in the Midst of Suffering and Evil* (Colorado Springs: Multnomah, 2009), 453.

the victory." It's not finding a religious truism to short-circuit the process. And it's not wallowing in heartache and self-pity. God is taking us in his direction. Ask. Seek. Knock. He found you first and he is willing to be found. 16

When Hannah was angry and upset because she could not conceive and have a child, the Bible says she took those emotions to God: "She was deeply distressed and prayed to the LORD and wept bitterly" (1 Sam 1:10.) Peter told the persecuted first-century church to bring their angst and worry to God: "Casting all your anxieties on him, because he cares for you" (1 Pet 5:7). King David, when facing fear in his life, took it directly to God in prayer: "I sought the LORD, and he answered me and delivered me from all my fears" (Ps 34:4). When Jesus faced His most distressing moments on earth, in preparation for his death on a cross, He prayed to God and shared all His emotion:

Then Jesus went with them to a place called Gethsemane, and he said to his disciples, "Sit here, while I go over there and pray." And taking with him Peter and the two sons of Zebedee, he began to be sorrowful and troubled. Then he said to them, "My soul is very sorrowful, even to death; remain here, and watch with me." And going a little farther he fell on his face and prayed, saying, "My Father, if it be possible, let this cup pass from me; nevertheless, not as I will, but as you will." (Matt 26:36-39)

This beautiful passage of Scripture records the most honest dialog between a son and his father. It paints the picture for Christ-followers to embrace, as it relates to how God has invited all who profess faith in him and enjoy a personal relationship to trust him with their most serious emotions.

In *Dark Clouds, Deep Mercy*, Mark Vroegop gives an honest explanation of these emotions or laments:

Complaint gives voice to our hard questions. Life is filled with a variety of suffering. Pain comes in many forms. Lament speaks into all the sorrows of life—no matter how small or big. Sorrow could enter your life because of unfulfilled longings, loneliness, an ailing body, or un unfair supervisor at work. It could come in the form of job loss, financial struggles, a broken engagement, or ongoing conflict in a marriage. Our hearts can groan under the weight of infertility, cancer, a failed adoption, an adulterous spouse, or wayward children. The longer we live, the more

¹⁶ David Powlison, *God's Grace in Your Suffering* (Wheaton, IL: Crossway, 2018), 45-46.

pain we see. God could intervene, but there are times—many times—when he chooses not to. That's the tension of complaint. 17

For those facing the fog of emotion and confusion, God is present. For those not sure what to do with these emotions and unsure how to clear the fog, follow the pattern of these brothers and sisters from the Bible. Allow Jesus to be the guide. Give these emotions to God. Process these feelings—all of these questions—with Him. He can handle it. All of it. God controls the weather; the winds and waves obey Him. He will burn the fog away.

¹⁷ Mark Vroegop, *Dark Clouds, Deep Mercy: Discovering the Grace of Lament* (Wheaton, IL: Crossway, 2019), 47.

CHAPTER 3

COUNTED WORTHY TO SUFFER

This chapter moves beyond the initial shock, confusion, and understanding of the "why" behind personal suffering, and shifts toward gaining clarity of the "what" God is doing through the difficulty of personal suffering. Continuing through our family's story, this chapter will show how the sovereignty of God brings supernatural comfort to the sufferer by demonstrating his divine provision and his ever-presence.

Calm

People always talk about the calm before the storm, and it is true that many times prior to a severe weather event, there is an eerie calmness, just before the storm hits. Before the thunder cracks and the lightning flashes and the trees are bent sideways by the fury of a major storm, there can be calm. Sometimes, the calm might include blue skies, as a lack of wind and a clarity in the air makes it feel totally strange. But there is also a calm *after* the storm. This calm does not get talked about much. I think it is usually ignored because everyone is so busy attempting to assess the damage from the storm, but it is a pleasant calmness just the same. People usually do not have to look far to see the after effects of the storm. Sometimes debris is strewn about, power might have been knocked out, or occasionally even buildings and houses have visible damage from the storm, but the weather is typically calm. The sun is often bright, and the wind settles into a breeze and actually serves to circulate the smell of clean air after a needed, cleansing rain. After Libby's storm had hit, and we had finished assessing all of the damage, we enjoyed a wonderful season of calm. The effects of the storm were visible to anyone paying attention, but the weather of our lives had calmed down.

Mary and I have grown fond of using the term "new normal" to describe our life after Libby. Of course, as we have grown and had more challenges, we have since discovered that eventually everyone has a "new normal" and that every time life demands a massive change or a major adjustment or significant loss, a "new normal" is what every person adjusts to thereafter, and so it was for us. Once we got through heart surgery and began to get some sense of "normalcy" to our family's rhythm, things started to settle into a routine and our family began to adjust to what this new life and these new challenges would bring.¹

With our older two children, Mary and I were pretty regimented about sleeping patterns and behavior. Both kids were in our room in a bassinet until about six or eight weeks old and then we moved them into their own room and into their cribs and we maintained this schedule with consistency, despite some of the hurdles that come with helping a newborn baby adjust to change. With Libby, however, all the rules went out the window. Libby slept in a bassinet in our room, followed by a pack-n-play in our room until she was about eighteen months old. Mary and I were so concerned with her medical fragility and had been so conditioned to try to avoid any additional complications, that we simply adjusted to this rhythm and made it work.

And this rhythm did work. Libby began to gain weight after heart surgery, something that she was unable to do prior. We began seeing specialists about her developmental delays, physical disabilities, and stayed on top of her medical frailty with her pediatric team. Libby was doing very well. When Libby was a baby, the average person would not have known anything was wrong. She did what all babies do. However, as Libby got older her delays became more noticeable and she began to miss milestones, which because of what the doctors had told us to expect, was not necessarily a surprise, but it is something we still grieve when they are missed, even today.

¹ I use "normal" in quotes as I know there is no such thing as "normal," and everything is subjective based on each person's individual perspective.

For Libby's first birthday, we blew it out. We probably invited fifty to one hundred people, including several of Libby's doctors who had become friends to Mary and me. It was an incredible celebration for our whole family, including our extended family who had walked each step of our journey thus far, right by our side. In fact, one thing I am grateful for is the incredible community God has given our family. We have immediate family that have walked alongside us and prayed for us in every challenge. God has also been gracious in giving us great friendships, churches, and even medical providers to partner with us through this life. This continues to be a blessing and evidence of God'

And so, we were adjusting. Getting used to our "new normal." Some of the fog of emotion was burning away. Not all of it, of course. There were certainly good days and bad days, good appointments, and a lot of bad ones too, but we were moving forward.

I do not know how she would not have, but Libby fit into our family immediately and perfectly. Mary and I were absolutely crazy about our little girl. Like each of our children, God had given us a unique and special love for her and there was not anything we would not do to provide for and protect her. Our older children also loved having a baby sister. They doted on Libby and cared for her from the moment we brought her home until today. Even though they were young, both children had an instinctive understanding that Libby was special and required more care than a typical baby brother or sister might have. One of the absolute blessings of God has been the way He has shaped our children's hearts by using their sister's disabilities to widen their capacity for love. God has used Libby to mold the most incredible spirit of tenderness, compassion, and care in both Kathryn and Coleman, and that is truer today than ever before.

Libby fit with us, and our family also fit around Libby. While it took a while for us to steady our legs beneath us again, once we adjusted to life with Libby, we went

right back into the busy routine of a young family with three small children, actively involved in our church and in the community where we lived. Once we began to catch our breath and move forward with our lives, adjusting to this "new normal" and the calm after our storm, God began giving our family a passion for other families who were themselves experiencing seasons of suffering. Whether that suffering was a child facing an illness or an individual with special needs, Libby had become a front door that allowed us to meet many wonderful people. We began to learn about the often forgotten, marginalized and least known people in society, the disability community. This is just one of the glorious ways God invites Christians to participate in his great drama of redemption. When Christian sufferers share in the suffering of others and comfort from a place of empathetic love and grace, the blessings are nothing short of supernatural.

In his book *Walking with God through Pain and Suffering*, pastor Tim Keller reminds his readers of how the apostle Paul knew first hand through affliction and suffering that God was using hardships to minister to others in suffering seasons. Keller writes.

Paul's sufferings drive him into God and his unfathomable comforts. We have been looking at many of those in this volume—deeper views of God's glory, and heart-changing appreciation of Christ's suffering, insights into life and human nature. What does Paul do with those insights? He shares them with others in affliction, who then through their sufferings find the deeper comforts too. The implication is that these sufferers in turn become comforters to others—and on and on it goes. The church becomes a community of profound consolation, a place where you get enormous support for suffering and where people find themselves growing, through their troubles, into the persons God wants them to become.²

I relate to the words of Paul and some of the hardships he suffered. I appreciate the redemptive lens by which he processed his pain. I can also admit that my learning through suffering has been slow and riddled with questions and confusion along the way.

As I continued to pursue my vocational calling into the ministry, God opened doors and made a way for me to transition out of the landscape business and into full-

² Timothy Keller, *Walking with God through Pain and Suffering* (New York: Penguin Random House, 2013), 193.

time ministry on staff at a large and well-respected church in the Dallas area. I learned so much so quickly from observing other ministers on the staff and discovering how a healthy church should work. I also continued my educational pursuits, attending seminary part-time and online. I was growing and learning ministry both through practical experience in the church where I worked, as well as in my studies and from professors who helped me discover the biblical and academic underpinnings for what I was called to do. However, the truth is that Libby best prepared me for the special responsibility of pastoral care.

Pastors and authors John Piper and Justin Taylor talk about the ministry of comfort in their book *Suffering and the Sovereignty of God*:

But when you've passed through your own fiery trials, and found God to be true to what he says, you have real help to offer. You have firsthand experience of both his sustaining grace and his purposeful design. He has kept you through pain; he reshaped you more into his image. You've found that what this entire hymn says is *true*. What you are experiencing from God, you can give away in increasing measure to others. You are learning both the tenderness and the clarity necessary to help sanctify another person's deepest distress. Second Corinthians 1:4 says it best: "[God] comforts us in all our affliction so that we will be able to comfort those who are in any affliction with the comfort with which we ourselves are comforted by God." That word "comfort" (or "encourage" in other translations) does not simply mean solace or inspiration. It means God's transformative compassion, the perfect union of kindness and candor. He speaks the truth in love so that we grow up to do the same. Notice how wise love is a "generalizable skill." What you learn from God in your *particular* affliction becomes helpful to others in *any* affliction.³

I have learned the ministry of comfort for others, through the ministry of being comforted by so many. This continues to be the testimony of God's grace in our family. Though, this calling is not reserved for vocational ministers or suffering parents. All Christians are entrusted with the gospel ministry of comfort. When Christ-followers use their experiences in and through personal suffering to serve others, their trials and pain are transformed into divine instruments of grace for others facing difficulty and hurt.

Libby taught me about the anxiousness that accompanies the surgical waiting room. Libby taught me what a family wants to hear from a visitor and what they do not.

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³ John Piper and Justin Taylor, *Suffering and the Sovereignty of God* (Wheaton, IL: Crossway, 2006), 166.

Libby taught me what words comfort a family in a moment of prayer and what words do not. Libby taught me about the disappointment of unfavorable test results and the letdown of a doctor's diagnosis. God used Libby to educate me in the privilege of pastoral ministry unlike any staff member or class professor.

Mary was experiencing the growth opportunities as well. Time after time friends would share the name and contact information of someone who had just received a difficult diagnosis for their child. Mary was continually asked if she would reach out and encourage that mother, and to pray with them. Sometimes Mary would be able to share learning experiences or a doctor's information, but other times she just listened to a devasted mom weep over her child, knowing Mary was a safe person for that to take place. I have watched with great joy as I have seen God use my bride countless times to minister to other parents and families who find themselves navigating similar waters to ours. Mary has a unique gift that the Lord has cultivated in her to exhibit unbelievable compassion and care for others who are suffering, while knowing intuitively the best ways to serve families in a practical way as they move ahead in their own journeys and struggles. We were learning, and God was using Libby as His instructor for the teaching. While things might be calm after our storm, there is always someone else in the middle of their own storm, and we are given a unique privilege to help them if we can.

Randy Alcorn explains the ministry of comfort that Mary and I were given:

The comfort God gives us in our suffering prepares us to comfort others who suffer as we have. One of God's purposes in our suffering is to prepare us to serve others, especially those who suffer as we have—for instance, from an addiction, miscarriage, abortion, infertility, divorce, or the loss of a spouse or child. Paul says, "The God of all comfort . . . comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God" (2 Corinthians 1:3-4). The common ground of suffering breaks down barriers of wealth, education, vocation and age. People in hospital waiting rooms often take an interest in one another's suffering and loved ones. They sail together on the same ship, riding the same rough waters.⁴

⁴ Randy Alcorn, *If God Is Good: Faith in the Midst of Suffering and Evil* (Colorado Springs: Multnomah, 2009), 429.

And in this ministry of comfort, Mary and I have the most incredible opportunities to speak of God's goodness and to boast in God's grace because of the suffering that our Libby has endured. I tell people all the time that while I might be a pastor, Libby is the greatest evangelist in the Bales family. She shares the gospel more eloquently without being able to speak a word than I ever could in a thousand sermons I might preach.

This is the redemptive aim of God in working through bad to bring such good.

This is what authors Larry Waters and Roy Zuck explain when they write,

Besides displaying one man's faith in God in times of suffering, the book of Job also has a "missionary" purpose. That is, a believer's suffering should be viewed, as seen in Job's experience, as an opportunity to witness not only to God's sovereignty but also to his goodness, justice, grace, and love to the nonbelieving world. Often the focus of the book of Job is seen simply as the sovereignty of God and man's faith response to God's will. But Job is also part of the progressive revelation of God's purpose and mission, so that in a sense the book is missional and evangelistic. As believers undergo undeserved suffering, they are witnesses to unbelievers of God's goodness, justice, grace, and love. Job is one of the first illustrations of an individual whom God used to demonstrate that mission involves God's redemptive purposes.⁵

God was at work in our family, through our story. It was painful to be sure, but there was no denying his goodness toward us throughout. Things had calmed down; the storm had passed and we were enjoying the calmer weather. We tried to help anyone we could to navigate their storms, as we were able to share what we had seen and learned through our own.

Between the therapies, doctors' appointments, my work, the older kids school and schedules, and all that was the rhythm of our regular life, things began to settle down in our world and we resumed a "new normal" life for our family. Mary and I began praying about growing our family, and once we had a peace about it, we decided to try for a baby again. After the disappointment of another miscarriage, we were blessed to find out that Mary was expecting, another little girl, and she was due in the middle of

⁵ Larry J. Waters and Roy B. Zuck, *Why, O God? Suffering and Disability in the Bible and the Church* (Wheaton, IL: Crossway, 2011), 111.

November 2011. Things were calm again, but *this time* things were calm *before* the storm and not after.

Counted Worthy

Much of life can be summarized in the memories being made while living it because memories are tied to moments of significance. Most of the time, the more important the event, the more powerful and vivid the memory will be that is associated with it. For example, when I was growing up, I remember my first home run in little league baseball—I have great memories tied to that. I remember the first time I went hunting with my dad—I have wonderful memories tied to that. I remember, as a child, when our home burned down—I have vivid and sad memories directly linked with that. I can remember some very competitive sporting events around the house with my two brothers—I have some funny memories tied to that as well. I remember my first date with Mary—I have some of my most tender memories in close connection with that.

Memories are images in our mind that trigger the recollection of significant moments and events from our life. The events surrounding the birth of our fourth child, our daughter, Hannah, have probably given me the single most vivid memory I have in my life. Certainly, the events around my salvation, my marriage, the birth of our children, and my calling into the ministry are also special and each unique. But with Hannah I experienced what has been the most powerfully surreal moment I have ever known, and it has changed my life since.

Mary's pregnancy with Hannah was completely normal. Like all of her pregnancies before, Mary had not experienced any unusual symptoms and there were no problematic findings during any of her doctor's appointments. Yet, because of the severity of Libby's genetic condition and in an abundance of prudence and caution, Mary's doctor insisted that we see a prenatal specialist in coordination with his ongoing care throughout the pregnancy. This process included some genetic counseling from a genetics specialist in the doctor's office. She made sure we were made aware of our

options for genetic testing in utero and then, depending upon those findings, all of the options for response, most especially the option for termination if desired.⁶ I appreciate how mother and author Stephanie Hubach elaborates on the value of human life and the understanding of the *imago Dei*:

When the image of God within is central to our understanding of humanity, it sends a powerful message about human value to the world around us. Our culture often measures personal value as a function of productivity. The degree to which we are able to contribute to society is the degree to which we are valued. In God's economy, however, human value is defined by the Creator himself through the imprint of his image in mankind. Others take notice, not merely when we say this is true, but when we live like it is true. Our actions ought to declare, "You are incredibly valuable!" to everyone we meet. In the same way, the *powerful message* of the gospel is demonstrated when we respond to others in grace-based actions. Our competitive culture is uncomfortable with the concept of weakness. When people see us acknowledge our frailties and intentionally engage others in the areas of their brokenness, we live out the gospel of grace in powerful ways.⁷

What a powerful picture this paints as to the value, dignity, and worth of all human life.

This is the value that Mary and I have always held and one which anchored us in the most difficult moments along the way.

When we were getting down to the end of Mary's pregnancy with Hannah, because Libby had come early, we were better prepared in case Hannah decided to do the same. However, in God's perfect timing, at almost thirty-eight weeks, on October 31, 2011, at 1:25 p.m. Hannah Jane Bales was born weighing 5 lbs. 12 oz. Unlike any of our deliveries before, but because of our family's new medical history with Libby, there were a host of people in the room for Hannah's arrival. There were extra doctors and nurses, which proved to be a good thing because Hannah, like Libby before her, needed extra

⁶ Termination would never be an option for our family to consider; our biblical convictions have taught us that all life is a gift from God and every person has been created in the image of God. In fact, the Bible teaches that humanity is distinct from the rest of creation in this truth: "Then God said, 'Let us make man in our image, after our likeness. And let them have dominion over the fish of the sea and over the birds of the heavens and over the livestock and over all the earth and over every creeping thing that creeps on the earth'" (Gen 1:26). Therefore, because humanity bears God's image and has been made in His likeness, all human life has an intrinsic value, dignity and worth, none of which is contingent upon ability, gifting, or health.

⁷ Stephanie O. Hubach, *Same Lake Different Boat: Coming alongside People Touched by Disability* (Phillipsburg, NJ: P & R, 2006), 49, emphasis original.

support to regulate her breathing and was taken relatively soon after delivery to the NICU for close monitoring and care.

Despite the ease of Mary's delivery, and in the absence of any complications associated with Hannah's birth, our little girl still needed some extra time to develop and receive that added support that a NICU can provide. Hannah went through a fairly extensive litany of tests and close observation while staying at the hospital. The added attention was in part because her lungs needed strengthening and she needed to learn how to feed without stressing her body out by not breathing efficiently while she did it. Additionally, and probably more importantly, Hannah received extra attention and focus because of Libby's medical history and the similar ways the two girls presented at birth. Unlike Libby, however, Hannah did not have any cardiovascular defects and she did not have any malformations of her hands or feet. She did, however, have a polycystic left kidney, which was detected without major concern in utero, and she was also pretty small for being almost full term at delivery. All in all, Hannah was a seemingly much, much healthier baby than her older sister Libby; she had no heart defect and no malformation of her feet. It seemed like we should have been relieved.

Mary and I did not have a peace about her health, though we desperately wanted to. We tried to convince ourselves that because she did not have the same obvious medical problems as Libby, that certainly she would not carry a similar diagnosis. Unfortunately, we could not shake our suspicion. Our pediatrician and the hospital neonatologist agreed that we had cause and justification to have Hannah's labs taken and for genetic testing to be done so we would know one way or the other for sure, so we decided to move forward with the genetic tests. While staying at the hospital and recovering in the NICU, Hannah's blood work was drawn and submitted to the laboratory for the genetic mapping to be done so we might know if there was anything abnormal.

After only seven days in the NICU, with Mary and I adopting the same routine of visitation as we had used with Libby, we were able to bring our little girl home. We

were thrilled to settle back into our routine. Libby was in full swing with therapies, both Kathryn and Coleman were rocking along in school and extra-curricular activities, and our family moved quickly through the holidays and toward Christmas, adjusting to our "new normal" yet again. This time we were a family of six, with a newborn baby right in the thick of it. Mary and I were doing well. Kathryn, Coleman, and Libby were doing well. And Hannah was doing well, although Mary and I had never escaped that suspicious feeling about her long-term health and we remained anxiously curious about the findings from the lab.

December 2, 2011, began as a typical Friday for our family. Fridays are usually the day of the week when I am out of the office and able to be most available to Mary and our kids for family time. This particular Friday fit right into that mold. Mary and I had planned that evening to spend time with several of our small groups from church who were hosting Christmas parties that we had been invited to attend. It was scheduled to be a Friday like every other, until the phone rang. Mary came in with a concerned look on her face and told me that the pediatrician had called. She said the doctor told her that Hannah's lab results were in and he asked if we could stop by his office to discuss the findings. We knew. Without hearing a word definitively, we both knew. We called my mom and arranged for her to watch the other kids at our home while we went to the doctor's office that afternoon for this appointment.

I will never forget the moment when our pediatrician told us, in what felt like slow motion, that the lab results revealed that Hannah had the exact same chromosomal abnormality as her sister, Libby. Although it was a mathematical impossibility, Hannah was diagnosed with Trisomy 16p.

Mary and I sobbed. Our doctor cried with us. "I'm so sorry guys. I'm just so sorry." That is all he could muster as he watched our hearts break right in front of him. We were wrecked. I could not catch my breath. His little office began closing in on us, and I could not reconcile what it was we were hearing. "Here we go again. God, I can't

do this again." These thoughts immediately flooded my mind. We were undone, devasted and destroyed, all over again.

Our doctor told us that he too was shocked for all of the scientific and mathematical reasons we had already discussed. He went on to say that he would have thought the lab confused Hannah's results for Libby's, if the director of the laboratory himself had not called him personally to confirm that after repeating the test twice, the results were accurate. On paper, Hannah is a genetic twin of her sister, Libby. I do not know the odds of this, and frankly I do not care, but as you might have guessed by now, we are in rare air with our girls. And if I am being honest, in that doctor's office that day, in that moment with that diagnosis read, it felt hard to breathe.

It took more than a few minutes for us to gather our composure. Everything had gone from the slow motion of the doctor sharing the test results to the speed of light as my mind began to race to all of the unknowns that come with Trisomy 16p. Our doctor kindly gave us all the time we needed to collect ourselves, and Mary and I waited until we were composed enough to walk out of his office without scarring all of the other children and families who were there to be seen. We hugged the doctors as we left, crying all over again on their shoulders, and we made our way slowly to my car.

Now, I believe in the supernatural. I do, completely, but I also admit that some of what people attribute to the supernatural is not, and if that makes me a skeptic, then so be it. Nevertheless, I believe in the supernatural. And what happened when Mary and I got into our car that day, I can only attribute to the supernatural work of God. When we got into the car, before we turned the ignition to start it up, I looked over at Mary and grabbed her hand. There was nothing supernatural about that, but there was something absolutely supernatural about what happened next. In my spirit, I felt God the Holy Spirit speak to me these words, "I have counted you worthy to get to do this *twice*." As clearly as I am writing this now or if speaking it out loud in person, God spoke into my spirit that phrase exactly. We had been counted worthy. I looked over at Mary and through even

more tears I shared what I felt God had just told me and she completely agreed, she felt it too. We were counted worthy by the God of the universe to care for, shepherd, protect, steward, provide for, teach, learn from, and love these two precious and rare gifts from God Himself. Also, because we have been entrusted with both Libby *and* Hannah, then God has counted us worthy to get to share in this joy *twice*.

Author Elisabeth Elliot rightly describes suffering as a gift when she says,

But when we're talking about the gifts of God, we're talking about gifts that come from One who knows exactly what we need even though it is not necessarily to our tastes and preferences. And he gives us everything that is appropriate to the job that He wants us to do. And so, understanding that, the we can say yes, Lord. I'll take it. It would not have been my choice but knowing You love me, I will receive it and I understand that someday I'm going to understand the necessity for this thing. So I accept it. And then I can even go the step beyond and say thank You. Thank you, Lord.⁸

Admittedly, it seems strange to speak of suffering as a gift, but in the hands of our redeeming God, that is exactly the way in which my family and I have grown to understand it.

In sharing this miracle moment, I do not want the reader to see our story and celebrate my response to suffering, but to celebrate *God*. My whole perspective changed in an instant, and not in any way because my circumstances did. No, I still had two daughters with very severe special needs, a massive amount of medical complications, and a bleak prognosis for their lives. My perspective changed because my privilege was found. I do not mean to trivialize the difficulty of our journey; it is hard, and I share more about that in the sections ahead, but it is also rewarding and truly a privilege that God would entrust the care of these rare gifts to us. This phrase "counted worthy" changes everything by allowing God's glory to be seen in our story and in our suffering.

Similarly, every sufferer has been counted worthy to endure something, and God is using it to build something in them and show something great about himself

⁸ Elisabeth Elliot, Suffering Is Never for Nothing (Nashville: B & H, 2019), 59.

through them. Authors D. A. Carson and Kathleen Nielson, in their book, *Resurrection Life in a World of Suffering*, write,

Let's say it right out and wonder at it: suffering is actually part of God's plan (and so necessary) to bring about the shining riches of praise and glory and honor. Glory is shining forth of God's very being. His glory is what he's after, shining forth even in us! Gold can't begin to picture it. Of course we cannot understand this glory without beginning at the cross, with the suffering of our Savior on our behalf. There was glory revealed. As we trust our Savior and then follow after him, what the apostle Paul says is true: our present sufferings are not worth comparing with the glory that is to be revealed in us (Rom. 8:18) – an eternal weight of glory (2 Cor. 4:17).

I would encourage sufferers to stop and think about whether their suffering, as difficult and painful as it might be, is not something they might have been entrusted with for a purpose greater than they could ever know without it? What has that sufferer been counted worthy to endure? Who has the suffering person or family been counted worthy to love? Perspective changes when privilege is found. It is a privilege that God has counted Mary and I worthy to be the parents of each one of our children, and in particular, Libby and Hannah.

Clarity

A few years ago, my eyesight began to diminish; it seemed to occur in perfect coordination with my turning forty. It felt like this change happened overnight and I have needed the help of reading glasses ever since. I first noticed this decline when I was reading a menu, but I chalked it up to bad lighting in the restaurant. However, my eyesight got worse. I was having a hard time seeing words clearly enough to read anything as quickly as I wanted, unless, on those rare occasions, I discovered that perfect distance to hold the paper or book away from my face, so everything came into focus. After struggling for a while, both with my eyesight and perhaps even more with my vanity, I went and got fitted for glasses and discovered what an unbelievable difference

⁹ D. A. Carson and Kathleen Nielson, *Resurrection Life in a World of Suffering* (Wheaton, IL: Crossway, 2018), 53.

clear vision could make. The clarity of sight because of the addition and benefit of glasses changed everything. Clarity always does.

In a similar way, I felt the unbelievable difference in God granting me the clarity of calling in the parking lot of our pediatrician's office that December day in 2011. On the heels of a devastating diagnosis, and what I thought would be a downward spiral for the second time, I discovered that God had already begun to work out the most clarifying reality for me and that He was using the journey with Libby and Hannah to do it.

As I mentioned previously, after we began to adjust to our "new normal" with Libby and we began to embrace the challenges this life often came with, we jumped head first into the ministry aspects that come with having a family member or friend with a chronic illness or some type of special need. God began growing us through both His Word and our own personal experiences in a deeper understanding of how His sovereignty and goodness worked, most especially in the midst of unexplained suffering and tragedy. One morning in my personal devotion I found myself reading the familiar passage I referenced earlier from John 9, but this time my perspective was different. Rather than simply staying confused as I had been before, God gave me some of the greatest clarity in my life as the powerful words of Christ leapt off the pages of Scripture and into my heart:

As he passed by, he saw a man blind from birth. And his disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?" Jesus answered, "It was not that this man sinned, or his parents, but that the works of God might be displayed in him. We must work the works of him who sent me while it is day; night is coming, when no one can work. As long as I am in the world, I am the light of the world. (vv. 1-5)

In the same way that I had struggled in the fog of confusion about Libby's suffering, the disciples were looking for a reason that the man was born blind. The disciples sought an explanation as to what unmerited human suffering could be attributed to, at its origin. and in some ways, so did I. On this particular morning, however, what jumped out at me from these pages of Scripture was clear. In His reply, Jesus meets His disciples' question head on. Author Gerald L. Borchert explains it this way: "Jesus, however, refused to accept the disciples' alternative of blame and in fact shifted the base system of the discussion from

blame to the grace of God in the face of human need. The story line thus signals that in this pericope Jesus was going to use the man's tragedy to reveal the works (*erga*) of God (9:3).¹⁰

This is another of the characteristics that I am so grateful for in our Savior. He is unafraid of and unapologetic about the truth. His answer is tremendously controversial, but completely thorough, and altogether helpful. Jesus' response is that this man's disability is not a consequence of personal sin and additionally not any consequence of that man's parents' sin. Leon Morris offers a technical explanation: "Jesus decisively rejects both alternatives. Suffering is not always due to sin, and this blindness is not the result of sin either in the man or his parents. "But" translates a strong adversative: "on the contrary," "far from that." It happened so that God's works might be shown in the man."

Jesus sought to dismiss not only their own narrow view, but also any potential extended application from their line of reasoning. Morris continues: "This does not, of course, mean that God made the child suffer blindness for years so that the cure might reveal his greatness. Rather, "God overruled the disaster of the child's blindness so that, when the child grew to manhood, he might, be recovering his sight, see the glory of God in the face of Christ" (Bruce)." Jesus thoughtfully and purposefully dismantles any bad ideas that surround the realities of the fallen and broken world. Jesus explains that God is not punitive in causing someone to suffer, but rather, is gracious in His working good in the midst of the suffering. Author Dave Furman summarizes this idea: "Our frail bodies are not a mistake. Our frailty is not a surprise to God nor are we weak as a result of him being powerless to give us stronger bodies. The fall brought disease and death, but

¹⁰ Gerald L. Borchert, *John 1-11*, The New American Commentary, vol. 25A (Nashville: Broadman & Holman, 1996), 313.

¹¹ Leon Morris, *The Gospel according to John*, The New International Commentary on the New Testament (Grand Rapids: Wm. B. Eerdsman, 1995), 425.

¹² Morris, The Gospel according to John, 425.

through our weaknesses, God shows off his all-surpassing power—to us and to the world "13"

In his grace, Jesus emphasizes that the object deserving the most curiosity is not in fact the blind man, but God who works in him. Again, verse 3 says, "Jesus answered, 'It was not that this man sinned, or his parents, but that the works of God might be displayed in him." Author J. Ramsey Michaels expounds on the working of God:

What he is saying, of course, is not that the man and his parents are entirely without sin, but that sin is not the reason for the man's predicament. He views the man's blindness from birth not as a tragedy but as opportunity. This is commonly understood to mean that the man's blindness affords Jesus an opportunity to work a miracle. The "works of God" are understood to be the works of Jesus. 14

The point is clear: God is always working. Perhaps in the things people identify as "good" the evidence of God's work is more obvious at first, but the reality of his handiwork is equally as true in the things identified as "bad" as well. Jesus makes this clear for his disciples and the Bible has preserved that clarity for us.

The reality of whatever suffering, circumstance, or difficulty a person faces is never actually about that suffering, circumstance, or difficulty. It is always about God, who is actively at work in those things. Keller gives a brief summary of Christ's work here, when he says, "In John 9, Jesus heals a blind man and takes pains to show his disciples that he was not in that condition because of his sin or that of his parents, but in order to fulfill God's inscrutable purposes." Likewise, Randy Alcorn offers an insightful and illustrative explanation of this New Testament story found in John 9:

God can use suffering to display his work in you. When Christ's disciples asked whose sin lay behind a man born blind, Jesus said, "Neither this man nor his parents

¹³ Dave Furman, *Kiss the Wave: Embracing God in Your Trials* (Wheaton, IL: Crossway, 2018), 96.

¹⁴ J. Ramsey Michaels, *The Gospel of John*, The New International Commentary on the Old and New Testament (Grand Rapids: William B. Eerdsmans, 2010), 541.

¹⁵ Keller, Walking with God through Pain and Suffering, 135.

sinned" (John 9:3). Jesus then redirected his disciples from thinking about the *cause* of the man's disability to consider the *purpose* for it. He said, "This happened *so that* the work of God might be displayed in his life." Eugene Peterson paraphrases Christ's words this way: "You're asking the wrong question. You're looking for someone to blame. There is no such cause-effect here. Look instead for what God can do" (MSG).

Nick Vujicic entered this world without arms or legs. Both his mom and his dad, an Australian pastor, felt devastated by their firstborn son's condition. "If God is a God of love," they said, "then why would he let something like this happen, and especially to committed Christians?" But they chose to trust God despite their questions.

Nick struggled at school where other students bullied and rejected him. "At that stage in my childhood," he said, "I could understand His love to a point. But . . . I still got hung up on the fact that if God really loved me, why did He make me like this? I wondered if I'd done something wrong and began to feel certain that this must be true."

Thoughts of suicide plagued Nick until one day the fifteen-year-old read the story in John 9 about the man born blind: "But that the works of God should be revealed in him" (NKJV). He surrendered his life to Christ. Now, at age twenty-six, he has earned a bachelor's degree and encourages others as a motivational speaker.¹⁶

And for this dad, perhaps the single greatest reality for me of what Jesus said when He answered the disciples' question and spoke of the works of God in suffering is that this declaration is given *prior* to the healing taking place. God is at work, and His work is not contingent upon healing happening as one might have asked or expected that it should. God is absolutely, completely, totally, and lovingly at work in Libby and Hannah's life, and that declaration is 100 percent true, regardless of whether He heals them on this side of eternity or the other.

Do I still pray for healing? Yes, all the time. Almost every day. Sometimes the prayers are little. "God would you please ease whatever is bothering the girls since they can't tell us what hurts? God, would you allow this meeting with the girl's teacher to be positive and encouraging as we gauge the progress they've made?" Other times, it has been huge. "God would you please stop the seizures. God I'm begging you, would you clear out the pneumonia? God would you realign their chromosomes in their sleep?" Yes, I've prayed *that* prayer many, many times. Why? Because He could. Sometimes God has

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¹⁶ Alcorn, *If God Is Good*, 394-95.

answered the little ones, and sometimes He has not. Sometimes God has answered the big ones, and sometimes He has not. Though, His workmanship is evident in their suffering, in their trials, and in our family's struggle, and it has never been contingent upon His healing for that to be true. Author D. A. Carson shares this comforting reminder: "What is clear is that it is in extremity that many Christians drink most deeply of the grace of God, revel in his presence, and glory in whatever it is—suffering included—that has brought them this heightened awareness of the majesty of God." I will share more in the chapters ahead, but the works of God in the life of our family are so obvious and gracious and good. It is God's good work in our girls lives that led me to write this thesis.

Again, I resonate with Stephanie Hubach's words when she writes,

It's time To Tell the Truth about disability: it is a normal part of life in an abnormal world. We are all recipients of the blessedness of creation and the brokenness of the fall. Upholding a biblical perspective of disability really matters, because when we see our world truthfully, we can view ourselves more correctly. When we view ourselves more correctly, we can also regard others more accurately. And when we regard others more accurately, we are more likely to respond to them appropriately. ¹⁸

My girls' value is intrinsic and given by God who made them. This value and worth does not change based upon ability *or* disability. Therefore, while the suffering is tough, God's work in and through those challenging moments is just as tangible and powerful as any physical healing and restoration might also provide.

However, because physical healing is not the only evidence of God's work, does this mean that God does not care about suffering? Absolutely not. The book of Hebrews explains that Jesus Himself is an empathetic High Priest, interceding on behalf of those whom He has saved (4:14-16). Paul Tripp explains God's understanding of suffering:

¹⁷ D. A. Carson, *How Long, O Lord? Reflections on Suffering and Evil*, 2nd ed. (Grand Rapids: Baker, 2006), 218.

¹⁸ Hubach, Same Lake Different Boat, 31-32.

Crying out to God in your moment of need is like talking to a dear friend whom you are comfortable talking to because you know that she knows exactly what you are going through. But there is more. God not only understands the broken space that is our current address; he inhabited that space in the person of his Son Jesus. This means that the One to whom you cry has firsthand knowledge of the things you're dealing with. It is frustrating to every sufferer to share their travail with people who don't have a clue and can't relate because they have no firsthand knowledge of what you're talking about. Jesus is not just a student of our suffering; he became a firsthand participant in it.¹⁹

Of course God understands suffering. He has experienced it on a deeper and more personal level than anyone else in history.

Likewise, Dave Furman explains the empathy of God in his book *Kiss the Wave* when he writes.

Jesus faced all the pain and disappointment of life as a human being. He knows how it feels to be tempted and to suffer loss. Jesus knows what it is like to cry tears, to feel betrayed. He was rejected by those close to him, and he felt physical affliction. He was ignored by his friends, and he tasted death. Jesus identifies with us in every way. He faced torment at the greatest level when he was forsaken by God the Father at the cross, crushed by the wrath of God and the weight of our sins. Even in our worst trials, when the waves are crashing upon us, we can say in faith: "Jesus you understand. You understand what I am going through." And he does. He understands what it's like to be a teenager. He understands what it's like to have shooting nerve pain in his body. He knows what it's like to be poor, to be mocked, beaten, and abused. He knows what it's like to be betrayed by a friend. He knows what it's like to face trials as an innocent one. He knows. He understands our pain. How comforting that he "gets" us.²⁰

This personal connection and actual experience makes God trustworthy and one in whom all sufferers can look to find enduring comfort.

Suffering can look many different ways and take many different forms, and God cares about all of it. Jesus has been betrayed. Jesus has been persecuted. Jesus has lost loved ones. Jesus has suffered physically. He knows. He gets it, and He cares deeply for those that are suffering. Joni Eareckson Tada, a fellow sufferer and personal hero to me and my family, talks about God's understanding of suffering, along with her coauthor Steven Estes in their book *When God Weeps*:

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¹⁹ Paul David Tripp, *Suffering: Gospel Hope When Life Doesn't Make Sense* (Wheaton, IL: Crossway, 2018), 109.

²⁰ Furman, Kiss the Wave, 45-46.

This is good news for the suffering soul. The Son of God did not exempt himself from affliction but lived through it and learned from it. Once that process was complete, he became the source of help for all who obey him. Should we suffer? "A student is not above his teacher, nor a servant above his master," says the One who learned obedience from what he suffered. "It is enough for the student to be like his teacher, and the servant like his master" (Matthew 10:24-25).

We open our Bibles and find that God has his reasons for allowing suffering, not just in the larger realm, but in the life of the individual. Learning some of those reasons can make all the difference in the world." ²¹

God is actively, purposefully, and redemptively working through suffering. He is using experiences of hardship, as one who has endured them just the same.

Jesus said in the Sermon on the Mount,

Therefore I tell you, do not be anxious about your life, what you will eat or what you will drink, nor about your body, what you will put on. Is not life more than food, and the body more than clothing? Look at the birds of the air: they neither sow nor reap nor gather into barns, and yet your heavenly Father feeds them. Are you not of more value than they? And which of you by being anxious can add a single hour to his span of life? And why are you anxious about clothing? Consider the lilies of the field, how they grow: they neither toil nor spin, yet I tell you, even Solomon in all his glory was not arrayed like one of these. But if God so clothes the grass of the field, which today is alive and tomorrow is thrown into the oven, will he not much more clothe you, O you of little faith? (Matt 6:25-30)

Those experiencing suffering are not birds or wildflowers, but are God's image bearers in creation, have been imprinted with God's image and likeness, and are infinitely valuable to God. God knows the person suffering and God deeply cares about them in the midst of suffering. My daughters have never faced a surgery, hospital stay, or doctor's appointment or therapy that God was not keenly aware of, completely involved in, and deeply concerned for—never. That is clear, and that clarity gives comfort. Tada reminds sufferers of this work of God in her book A Place of Healing: "While I'm not saying God enjoys watching us struggle, His Word clearly indicates He allows wounds to prick and pierce us. But that doesn't mean He has stopped caring. God expresses His care in

²¹ Joni Eareckson Tada and Steven Estes, *When God Weeps: Why Our Sufferings Matter to the Almighty* (Grand Rapids: Zondervan, 1997), 115.

different ways. As many have said so eloquently, sometimes He delivers us from the storm and at other times He delivers us through the storm."²²

Finally, in expounding on this truth, Jesus goes further with his thought by saying, "We must work the works of him who sent me while it is day; night is coming, when no one can work" (John 9:4). This verse might be the most misunderstood of the first four from this chapter. Jesus appears to be explaining to His disciples that all things, including suffering, should be seen in light of God's ability to work through them, as long as one is alive. Jesus adds a temporal component to the question. In addition to the question held as to the cause of the blind man's condition, Jesus elects to address an apparent eschatological truth in His response to his disciples at the same time. Jesus places an emphasis on God's glory being made known *now*, referencing the idea that at some time in the future there will be no more work done. God's glory will continue to be known, but it will not involve any suffering for it to be seen. There will be no more work in suffering because there will be no more suffering. This is such good news.

Authors John Piper and Justin Taylor express this incredible hope when they write,

When we are in the pit of despair we must look around and see that only God can bring us out. There is no other hope. And what's more is that God himself is committed to bringing us out. He alone is holy and therefore he alone can help us. Yes, the night is long and the weeping intense, but the morning is coming. And as we wait for the coming dawn, the return of the Son of God, we can know that we are not alone. While we are on earth, there often will be deliverance from many of our sufferings – there will be many mornings that will dawn and bring with them joy. But the ultimate morning comes when Jesus returns. That is when the true shout for joy will come and when all tears will be wiped away (Rev. 21:4).²³

Likewise, when speaking of this hope working in concert with sorrow, author Mark Vroegop shares,

²² Joni Eareckson Tada, A Place of Healing: Wrestling with the Mysteries of Suffering, Pain, and God's Sovereignty (Colorado Springs: David C. Cook, 2010), 57.

²³ Piper and Taylor, Suffering and the Sovereignty of God, 189-90.

Finally, we've seen that Christians lament expectantly. Knowing God's goodness and believing in his sovereignty cause us to pray for divine intervention to the painful paradoxes of life. We know the brokenness of sin that causes all lament. And we believe the death and resurrection of Jesus inaugurated the defeat of sin, death, and all tears. In our sorrow, we long for the day when lament will be no more: "He will wipe away ever tear from their eyes, and death shall be no more, neither shall there be mourning, nor crying, nor pain anymore, for the former things have passed away" (Rev. 21:4).

One of the greatest joys of the new heavens and the new earth will be the absence of all songs of sorrow. Perhaps we'll sing the Psalms, but we'll not sing all of them. In God's presence there will be no need to lament. All our complaints will be complete. Our requests will have been answered. Praise will be the air we breathe. Heavenly praise will replace our earthly groaning.²⁴

I am crying as I write this now, overwhelmed by the thought that there is a day coming when my girls will be whole. When they will never endure another test, never suffer another pneumonia, never convulse from another seizure. Libby and Hannah will walk with us, talk to us and run to Jesus. The apostle John visualized that day as recorded in the book of Revelation:

Then I saw a new heaven and a new earth, for the first heaven and the first earth had passed away, and the sea was no more. And I saw the holy city, new Jerusalem, coming down out of heaven from God, prepared as a bride adorned for her husband. And I heard a loud voice from the throne saying, "Behold, the dwelling place of God is with man. He will dwell with them, and they will be his people, and God himself will be with them as their God. He will wipe away every tear from their eyes, and death shall be no more, neither shall there be mourning, nor crying, nor pain anymore, for the former things have passed away. (Rev 21:1-4)

That day is coming, and I trust in God for each day between this one and that one. I endure suffering by trusting in God who is working in it and believing in God for the day it will be no more.

Again, I find strength in the words of authors who have shared their hopes for that glorious day to come. Tim Keller says, "The resurrection of the body means that we do not merely receive a consolation for the life we have lost but a restoration of it. We not only get the bodies and lives we had but the bodies and lives we wished for but never

²⁴ Mark Vroegop, *Dark Clouds, Deep Mercy: Discovering the Grace of Lament* (Wheaton, IL: Crossway, 2019), 193.

before received. We get a glorious, perfect, unimaginably rich life in a renewed material world."²⁵ Furman envisions this biblical hope, that the resurrection of Jesus has made into reality for those that will be found in Christ, by saying,

The truth of the resurrection gives us real hope. If you can't kneel and you can't dance and you can't run, in the resurrection you will dance perfectly. If you are lonely, in the resurrection you will have perfect love. If your heart is empty, in the resurrection you will be thoroughly filled. If you are depressed, in the resurrection you joy will be complete. Christian, if you are facing grave illness or even death, the resurrection gives you hope that in the moment you die, you will be with Christ.²⁶

The resurrected Savior gives sufferers a supernatural and transcendent hope that circumstance and momentary affliction cannot take away.

Finally, when Jesus answers the disciples' question, He also offers a shift in the focus in verse 4. Jesus shows that God is clearly the subject, not the sufferer nor the suffering. God, as "him who sent me" is clearly seen as the one to whom deference and glory belong. The writer even uses grammatical tenses to address a present problem from a future perspective. God is the hero in every story of suffering because He is the one working good in the midst of it. Those that are suffering might not always see it or be aware of Him while He is doing it, but the fact that it is being done is always true.

Author Elisabeth Elliot gets to the point quickly when she explains, "And I've come to see that it's through the deepest suffering that God has taught me the deepest lessons. And if we'll trust Him for it, we can come through to the unshakable assurance that He's in charge. He has a loving purpose. And He can transform something terrible into something wonderful. Suffering is never for nothing."²⁷

The idea of God at work in difficulty is woven throughout the Scriptures. Most Christians have heard some of these verses quoted at one time or another. Sometimes

²⁵ Keller, Walking with God through Pain and Suffering, 117.

²⁶ Furman, Kiss the Wave, 65.

²⁷ Elliot, Suffering Is Never for Nothing, 1-2.

they are shared out of context and in a way that is intended to help, but ends up hurting instead. ²⁸ Perhaps someone has shared Romans 8:28 with those suffering, in the middle of their pain: "And we know that for those who love God all things work together for good, for those who are called according to his purpose" (Rom 8:28). Those that are doubting this goodness should be reminded that if it is in God's Word then it is true, and it can be trusted. God's Word says *all things*—not *some* things, not *most* things, but all things.

Tripp gives help in understanding the goodness of God and the suffering of man when he writes,

When people lift Romans 8:28 out of its immediate context they understand it to mean what it does not mean. The way to understand any single Bible passage is to remember that Scripture interprets Scripture. The key to understanding the true hope of this passage is to understand the "good" that Paul is writing about. Verses 29 and 30 tell us. The "good" that is guaranteed in this passage is our redemption. Even before he made the world, God made the decision that his work in us would be completed no matter what. This means that the grace you and I reach out for in our times of trouble is never shaky or at risk; it is a present expression of a plan that was settled before this world began. It is so good to know that when things in you and around you have been damaged or compromised, nothing can damage, interrupt, or stop your true security, which is found in God and his grace poured out for you. This proper understanding of this wonderful passage gives hope even when you look around and have no hope.²⁹

So then, how can all things be working together for good unless God is involved? The world is completely broken, and sin has wrecked what God had made perfect. The consequences of this, then, are that without help or intervention, not all things can be working together for good because not everything is in fact good. But God, by the very definition of his character, is completely and only good. So, if God is *not* at work, then all things cannot be working together for good, but because God *is* at work, then things can work for good, because God Himself is good. Good does not happen apart from God. This is a reality, and certainly one which would include suffering. As discussed

²⁸ This type of hurt is discussed in the next section.

²⁹ Tripp, Suffering, 34.

previously, this unconditional goodness of God is why Jesus said that God's workmanship could be declared in the blind man's life, *prior* to his physical healing happening yet. By verses 6 and 7 of John 9, the blind man does have his sight physically, miraculously restored, but the declaration of God's workmanship came first.

David Powlison speaks of God's working good in the midst of bad: "Affliction itself is not good, but God works what is very good, bringing the ignorant and wayward back home. Faith's enduring and alert dependency on the Lord is one of the Spirit's finest fruits. And you bear that fruit only when you have lived through something hard." ³⁰

Still further, the apostle Paul says, "And I am sure of this, that he who began a good work in you will bring it to completion at the day of Jesus Christ" (Phil 1:6). God begins and finishes His good work. All of His work, even the good work He does through suffering. Likewise, this truth is echoed even in the Old Testament Scriptures as God promises His covenant people of His intention to work on and in their lives. Jeremiah 29:11 says, "For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope." God has good plans for His people, and that would certainly include plans that involved seasons of suffering for Israel.

Anyone who has ever tried to explain away God as being an uninvolved, uncaring, unapproachable being, absolutely does not know Him. Jesus wanted to communicate to His disciples in John 9, and on that particular morning wanted to communicate to me as well, that in the midst of this broken reality that is suffering, my focus should not be on the suffering itself, but rather on God who is at work, doing good in the middle of the suffering. I gained some much-needed clarity on the day that I was struck with a new understanding of John 9. My understanding of the goodness of God in the midst of suffering while holding in tension His absolute sovereignty over all of it, has grown. It is still growing, and I am still learning. In her book *Through Gates of Splendor*,

³⁰ David Powlison, God's Grace in Your Suffering (Wheaton, IL: Crossway, 2018), 21.

author Elisabeth Elliot says, "God is the God of human history, and He is at work continuously, mysteriously, accomplishing His eternal purposes in us, through us, for us, and in spite of us." Admittedly, this lesson has not always been an enjoyable one to learn and it has certainly come with more than a few broken-hearted, angry, and confused questions being hurled at God along the way. But I am learning. I am seeing more clearly, and clarity that comes from God is always a good thing. Those that are suffering must learn to rightly embrace a healthy theology of suffering: the works of God are not limited to or contingent upon the physical healing of God. God is not a God *for* the trials or a God *from* the trials. No, He is a God *in* the trials, working for the good of those who love Him and for His glory whether those suffering recognize it or not.

Cruel

One Christmas movie tradition that I know a lot of people practice is watching Hallmark holiday movies. As I understand it, each one of these movies seem to have the same basic formula with only variables in character and story. They all seem to similarly wind down with a very happy ending.

Maybe people have a growing fascination with these films because everyone knows that life is not really like a Hallmark movie. Not everything has a picturesque happy ending where the characters are smiling as the credits begin to roll. Life is hard, life is messy, and sometimes life can be flat out cruel. In fact, because sin is common to everyone, then likewise suffering is common to everyone as well. Author Elisabeth Elliot defines suffering this way: "Suffering is having what you don't want or wanting what you don't have." What is fascinating is that a limitless number of things cause people to be different, but there are few things that all have in common, and the one certain commonality shared between everyone everywhere is that all are sinners and everyone

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³¹ Elisabeth Elliot, *Through Gates of Splendor* (Carol Stream, IL: Tyndale, 1996), 263.

³² Elliot, Suffering Is Never for Nothing, 9.

has either already or will at some point experience suffering. Sin and its consequence of suffering are universal. No one escapes it.

In *Joy in the Sorrow*, author Matt Chandler describes the cruel commonality of suffering:

Suffering is the common denominator of all humanity in this world, isn't it? All of us are marked by scars of some sort, though not all are ones you can see. Waiting rooms and hospitals and gravesites do not play favorites. Rich and poor. Old and young. Every ethnicity and every generation. All under the same curse of a broken and bruised world where things do not work the way they were supposed to. Suffering is a part of every human experience.³³

In pastoral ministry, the questions, or a version of them, I am asked most often are, "Why do bad things happen to good people?" or "If God is good, why is their bad and evil in the world at all?" These are great questions. I will make my best attempt to answer them in this chapter but the burden beneath each question is rooted in the pain common to all. That pain is suffering. Our family has endured a great deal of suffering.

Between Libby and Hannah, we have made more emergency room visits than I can count. Our girls have had dozens of hospitalizations, totaling months and months of time admitted receiving treatment and care. Libby has had eight surgical procedures requiring full anesthesia and Hannah has had three. Libby has been admitted to the Pediatric ICU (PICU) three times with infections or pneumonia and Hannah has spent more than six weeks in the PICU in the last two years alone. When we lived in East Texas, we were transported by medical ambulance to a children's hospital in Dallas seven times and flown by air ambulance twice.

We have lived the ups and downs of trauma too. This includes the most terrifying moment of my life, when Hannah crashed from a severe bout with pneumonia in 2018. I stood at the foot of her bed in the emergency room and watched the doctor and nurses revive Hannah just long enough for a tube to be inserted down her throat and a

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³³ Matt Chandler, *Joy in the Sorrow: How a Thriving Church (and its Pastor) Learned to Suffer Well* (London: Good Book, 2019), 169-70.

unable to take in on her own. I will never forget the words of the emergency room physician who worked on Hannah that day: "It doesn't look good Connor, but we can get her to Dallas now." By God's grace, that doctor happened to be a close friend of mine, and he saved our daughter's life, but those moments, that scene, my emotions, and that hardship felt cruel. Hannah spent 31 days in the PICU with that round of pneumonia, having more than forty seizures every hour when her illness was at its worst. When things were most serious, at the encouragement of the doctors, I went home and pulled Kathryn and Coleman out of class to let them know that things had taken a severe turn and gave my best effort to prepare them in case she did not survive. Those are cruel conversations. Cruel. Yet, many people have it so much worse, and this is not a comparison. This is perspective. It is all suffering and it can all be cruel.

Suffering is not only the trauma and life-threatening moments we have endured. Sometimes the cruelty of suffering is simply the repeated blood draws and lab work that our girls' medicine regimen requires to ensure we are not risking any long-term organ damage from the chemicals they ingest. How does one explain to a non-verbal child with the cognitive awareness of a nine-month-old baby that the nurse has to stick them with a needle, but it is for their good? What about the repeated efforts to find the vein, only to miss, ultimately either sending us home without getting the needed labs or calling a care flight nurse to assist, in hopes that they will have better luck finding the right place to try? How do I explain that to our girls while they are crying and sweating from fighting while the procedure takes place? It seems cruel.

How about the indignity that comes with helplessness? Our girls are eleven and eight years old respectively, and both diapered, requiring total personal care. Very few places are equipped to accommodate diaper changes safely and discreetly, which leaves parents and families with awkward and unsanitary choices. This is only more

complicated once puberty has arrived, complicating the personal care for both the girls and for us as their caregivers.

Even the more progressive public restrooms, which have changing stations available, are almost always constructed only for babies and are not large enough to accommodate our girls and do not offer any privacy, which is a must to preserve their innocence and dignity. On a few occasions we have resorted to using a bathroom floor while someone stands watch to keep the door closed for privacy, but this is almost always a last resort as it is dirty and completely unsanitary. Most often we are sprawled out in the back of our minivan with one of the children assisting in holding a full size blanket as a screen in hopes of providing some privacy and maintaining as much dignity for the girls as we can. We have mastered this technique on road trips and like a NASCAR pit crew, everyone knows their role and I am proud to say that we can get a full diaper change done in minutes. However, I would not want to mislead those reading either, it is humbling. At times, it is humiliating. It can be cruel.

The cruelty of suffering is not just physical either. It can also be relational. I mentioned previously that most people who say hurtful things in the midst of someone's suffering, did not honestly intend to hurt them. I sincerely believe that. It has been my overwhelming experience that most people simply do not know what to say when someone is hurting, but they think they have to say something, so they occasionally say the wrong thing instead. David Powlison explains,

Suffering often brings a doubled pain. In the first place there is "the problem" itself—perhaps sickness or poverty, betrayal or bereavement. That is hard enough. But it is often compounded by a second problem. Other people, even well-meaning, often respond poorly to sufferers. Sufferers are often misunderstood, or meddled with, or ignored. These reactions add relational and psychological isolation to the original problem.³⁴

Well-intended, but poorly timed or woefully insensitive words can wound deeply. Our family has felt the pain on more than one occasion, but as a result, God has given us a

³⁴ Powlison, *God's Grace in Your Suffering*, 52.

sensitivity and thoughtfulness with our words offered to others in their own times of suffering and trial.

In their book *Why, O God?*, authors Larry Waters and Roy Zuck give needed wisdom in responding to those who are suffering:

The disturbing *why* question is haunting wherever suffering and disability rear their heads. "Why did this happen to me?" "Why doesn't God heal me?" "Why didn't God protect me from this?" In light of the Bible's presentation of the complexity of the causes of suffering, pastoral caregivers need not be frustrated by their inability to provide authoritative answers about causes. As in the case of biblical events, answers to the *why* question may remain buried in the unrevealed wisdom of God. As a result, caregivers would do well to anticipate a ministry of listening to unending questions without giving answers that are completely satisfying. Appreciation of the mystery of God's work in and through suffering brings with it a humility of service and a proper pause in providing answers.³⁵

I have arrived at the opinion that people often provide an unnecessary hurtful response based not only upon my own experiences in our family and with our girls, but in my pastoral ministry as well, through watching people engage and interact with others who are hurting around them.

Mary and I have often teased that we would want to write a book entitled *Stupid Things People Say to Help*. If it was to be written, I would include the story of the man who came up to me following a men's event where I had just finished preaching. In my sermon, I used a brief illustration on suffering and trials, and I shared a moment from a recent doctor's appointment with one of the girls. This older gentleman approached and kindly thanked me for my message and then asked if when I said special needs to describe my daughter, did I mean she was "retarded." Somewhat shocked, I said, "Yes, she has severe cognitive and physical disabilities." He went on to explain that he understood and had a grandson who was dyslexic and was having a difficult time learning to read. I smiled and nodded and moved on, but I was shocked and hurt. I do not tell that story to make fun of that man, I honestly do not believe he knew how insensitive his phrasing of that question and comparative analysis truly was. I also do not in any way

³⁵ Waters and Zuck, Why, O God?, 233.

diminish the significance and sincerity of dyslexia or any learning difference; they are all legitimate and challenging and painfully cruel in their own way. Suffering is common to all. The specifics of suffering differ as much as the people who experience them. I simply share that story as one example of cruelty in suffering, through relationships. I will offer one more.

When Libby was about three years old and Mary was pregnant with Hannah, we were fortunate enough to get Libby's first wheelchair. It was a great wheelchair. It was grey with pink trim and was customizable so that it could be adjusted as Libby grew. It was sturdy and would fit in the back of Mary's car, even though it was not totally collapsible, like a baby stroller. One day while pushing Libby in it, another young mom came over admiring the wheelchair and began to ask Mary about it. Mary bragged on how great it was and how much we loved the size and durability and then politely explained that it actually was not a stroller, which the other mother had assumed, but was a wheelchair for our daughter Libby (who was sitting in it at the time). The other woman replied, "Well do you know if I can get one for my normal kid?" Fortunately, Mary had another friend nearby who heard the conversation and to this day I am convinced that the Holy Spirit kicked in there as well. That friend grabbed Mary by the arm and without responding they walked away.

It would be wise to remember the words of James: "Know this, my beloved brothers: let every person be quick to hear, slow to speak, slow to anger; for the anger of man does not produce the righteousness of God" (Jas 1:19-20). For those who feel compelled to say something to someone who is experiencing a season of suffering, consider the first part of James' advice: "Let every person be quick to hear, slow to speak." People often get the order wrong. Albeit with good intentions and a motive that is pure, many are quick to speak and slower to listen.

However, because suffering is common to everyone, all will be granted opportunity upon opportunity to speak into the lives of those who are suffering. So, I

would remind the reader that James says to listen carefully. One might have an idea of an encouraging phrase to say, or what they are convinced the sufferer needs to hear, but listening carefully might be all that is needed, and when speaking, on should go slowly. The Proverbs warn about the danger of quick speech: "Do you see a man who is hasty in his words? There is more hope for a fool than for him" (Prov 29:20). I am writing this encouragement from experience. I have learned this the hard way, both as the offender and as the offended. I have heard it said that the formula for wise counsel is (1) prayer, (2) listening, and (3) response.

Randy Alcorn gives practical, biblical wisdom on this subject of speaking into another's suffering:

Jesus wept over the death of Lazarus and his bereaved sisters, Mary and Martha, not because he lost perspective, but because he had perspective. Death is an enemy, as is the suffering and disability that precedes death. God hates it. So should we. We are to rejoice for the coming day when God promises no more death and suffering. Such rejoicing can fully coexist with mourning great loss.

We should avoid spiritual-sounding comments that minimize suffering, such as "God must have loved your son very much to take him home this young." Parents who hear this will say, "Then I wish God loved him less." A friend told me that when her child died, a well-meaning woman assured her it was "for the best." My friend, a committed believer, said, "I wanted to tell her to shut up."

Do not say to a person whose child has died, "I know what you're going through; my mom died." It may have been difficult for you, it may help you empathize to a degree, but it is not the same. Those who suffer loss need our love and encouragement. They do not need us to minimize or erase their pain through comparison; they need to feel and express it fully.³⁶

People who engage with those in suffering should usually say *only* three things: (1) I am so sorry—it is critically important to acknowledge sadness and grief over whatever it is that one is suffering. (2) This is awful—every sufferer should be validated in their suffering with the acknowledgement that whatever they are facing and enduring is bad, for them. (3) I love you—the unconditional, gospel-reminder that to love and support one another in the midst of suffering is Christ's work in and through his people.

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³⁶ Alcorn, *If God Is Good*, 365-66.

In the Scripture from James, he was not only talking to those who tend to speak before they think. In fact, Mary and I would do well to remember the wise warning he offers in the second part of his advice: "Slow to anger; for the anger of man does not produce the righteousness of God." The next time someone says something hurtful to us, we would do well to remember that we need to be slow to arrive at our anger. It is not wrong for us to be hurt, that is natural, and James makes no comment against that.

However, when anger is born out of that hurt or anything else it becomes dangerous and could lead to sin. I confess that I have struggled with this. I have not always responded apart from anger and have certainly held thoughts which were rooted in anger. Though the formula for wise counsel works in response too: (1) prayer, (2) listening, and (3) response. These conversations are just some of the challenges of suffering and the cruelty which often accompanies the difficult circumstances that are a part of it.

Of course, cruelty in suffering is not only in the physical or the relational, but a terribly emotional element goes along with it too. When emotions are driven from one test to the next, from one hospitalization to the next, from one disappointment to the next, it can be emotionally exhausting. We are *always* the family stared at in public. There is not a restaurant we visit where some furniture does not have to be moved to accommodate our family as we are seated. I am so used to apologizing to others as we carefully navigate wheelchairs past their tables on the way to ours that I do not even think about it anymore.

Our girls both wear bibs over their shirts because they drool and chew on teething toys, a lot. They make strange noises and when they get excited, sometimes they will flap their arms or shake their head and wiggle in their chairs. We think it is adorable, but we also admit that if someone is not used to it, then it is abnormal and can seem weird. I totally get that. It would have been strange to me as well, before God blessed us with Libby and Hannah who taught me to love it.

When we are at the mall or at a store, most people look with pity, but some look with concern and a few look in disgust. One time, as we were leaving a restaurant, a woman wondered out loud to her table of friends, "What's wrong with those parents? That little girl is far too old to still use a pacifier!" I admit, both Libby and Hannah (ages 11 and 8 respectively) both still enjoy a pacifier. There are multiple medical and sensory related reasons I could give to explain this, but let me just summarize as their dad and tell you that we allow it because they both enjoy it. They are cognitively about nine months of age, even though they have the physical body type of their actual ages. Nevertheless, this comment infuriated me and when I calmed down, I realized that my anger was really just hurt feelings. Not my own but hurt for my girls who did not even know they were being judged and looked down upon. It felt cruel.

Likewise, anytime people attempt to explain their foolish or immature behavior by labeling it "retarded," I cringe in hurt and wince in anger. Yet before my girls, I could have easily been the one using that word as that type of adjective because I was just ignorant enough not to know any better. But now, on this side of things, it hurts. It is mean, it is cruel, and that cruelty has resulted in an overflow of emotions on so many occasions.

I have cried in doctors' offices, emergency rooms, hospital rooms, NICUs, PICUs, therapy sessions, school ARDs, school programs, Mary's arms, both my brothers shoulders, my friends shoulders, my home, my office, my truck on an interstate, the shower and a bunch of other places I cannot remember. Emotions are God-given and not to be ignored completely or submitted to entirely. They are to be handed over to God for processing.

I do not want to diminish how hard suffering can be. Life with our daughters is an unbelievable blessing. Truly, more than I could have ever imagined it would be, but it is also hard. Really, really hard. Within some Christian circles, there seems to be a way of thinking which communicates that if you struggle with suffering as a Christ-follower,

there must be something wrong with you. That is not true, and it has been terribly frustrating to deal with that lie on the occasions when it has been presented to me. I have encountered this dishonest thought in our personal journey, and I have witnessed it in my pastoral ministry as well. Suffering is not natural. God did not create suffering in the beginning. It is a byproduct and consequence of sin and the broken condition of our fallen world. So, it is okay to struggle. It is okay to admit that suffering is hard, and it does not make you a bad Christian or less of a Christian simply because the struggle in suffering is real. After all, cruelty in suffering is just, well, cruel.

But what about those huge questions I alluded to previously? The ones every pastor is asked and every sufferer, therefore every person, wrestles with at one time or another. "Why do bad things happen to good people?" or "If God is good, why is their bad and evil in the world at all?" These questions are theological. They are biblical. They are serious and worthy of a thoughtful, seriously biblical response.

Considering the theological implications of John 9 in its broadest sense, as it relates to the suffering of all humanity, Jesus promised God's work in the man born blind. One of the ways to see God's workmanship in suffering is that suffering reveals a brokenness that God alone can heal. All suffering points to all brokenness. Physical suffering says bodies are broken and only Jesus can restore. Emotional suffering says minds are broken and only Jesus can renew. Relational suffering says communities are broken and only Jesus can reconcile. Spiritual suffering says souls are broken and only Jesus can redeem.

Alcorn offers a theological explanation of suffering and evil when he says,

Secondary evils point to primary evil, reminding us that humanity, guilty of sin, deserves suffering. Secondary evil, the direct and indirect consequences of primary evil, provokes our indignation. Why do innocent people suffer? God hates the primary evils we commit, while we hate the secondary evils (consequences) God determines or permits.

As humans, however, we all stand guilty. Although many secondary evils befall us even when we have not directly committed a sin that causes them, we would not have to deal with secondary evils if we did not belong to a sinful race. Short-term suffering serves as a warning and foretaste of eternal suffering. Without a taste of

Hell, we would not see its horrors nor feel much motivation to do everything possible to avoid it. Hence, the secondary evil of suffering can get our attention and prompt us to repent of our primary moral evil.³⁷

The eternal effects of sin are why Jesus used this man's physical ailment to reveal a greater spiritual need. One should consider the gospel implications in this text. We are all born spiritually blind. No one, on their own, is able to seek truth and discover God's salvation, but by the grace and mercy of God and through faith in Jesus Christ, all can see and experience the salvation of God and the forgiveness of sin. This blind man's physical condition was used by God as His workmanship to reveal the greater spiritual need.

Paul says similarly, when he writes to the church in Corinth:

And even if our gospel is veiled, it is veiled to those who are perishing. In their case the god of this world has blinded the minds of the unbelievers, to keep them from seeing the light of the gospel of the glory of Christ, who is the image of God. For what we proclaim is not ourselves, but Jesus Christ as Lord, with ourselves as your servants for Jesus' sake. For God, who said, "Let light shine out of darkness," has shone in our hearts to give the light of the knowledge of the glory of God in the face of Jesus Christ. (2 Cor 4:3-6)

Any sufferer looking at his own season of trial for the purposes of finding meaning, significance, and hope only in the immediate and temporary reality of this life now will miss the greatest evidence of God's workmanship and the glory that is the gospel. Jesus has come to deliver his people from all the brokenness of sin and suffering for eternity, even if the relief that is desired does not happen in the here and now. All suffering, regardless of whether it is understood or not, points to a brokenness in and around humanity that God alone can restore.

Tim Keller expresses this work of God in the specific tragedy of suffering as central to the Christian faith:

The Christian understanding of suffering is dominated by the idea of grace. In Christ we have received forgiveness, love, and adoption into the family of God. These goods are undeserved, and that frees us from the temptation to feel proud of our suffering. But also is the present enjoyment of those inestimable goods that makes suffering bearable.³⁸

³⁷ Alcorn, If God Is Good, 27.

³⁸ Keller, Walking with God through Pain and Suffering, 29-30.

Again, this idea of spiritual blindness is pointed to elsewhere in the Scriptures. When Paul is pleading his case before King Agrippa and sharing his own story of salvation, he recalls the very words Jesus spoke to him regarding the reality of spiritual blindness from which everyone suffers. Acts 26:16-18 says,

But rise and stand upon your feet, for I have appeared to you for this purpose, to appoint you as a servant and witness to the things in which you have seen me and to those in which I will appear to you, delivering you from your people and from the Gentiles—to whom I am sending you to open their eyes, so that they may turn from darkness to light and from the power of Satan to God, that they may receive forgiveness of sins and a place among those who are sanctified by faith in me.

Jesus answers the question and uses the example of the man's blindness from birth, and subsequent suffering, as a platform that reveals God's workmanship from a greater spiritual suffering; a suffering from which Jesus is the only one who can deliver. This deliverance is where I find my greatest strength for Libby and Hannah. Jesus lived a life only he could live, and died a death that everyone else deserved. He rose for the salvation of mankind so that all might spend eternity with God. Whether they know they need the forgiveness of God or not, it is my biblical conviction that Jesus has secured it for them. I firmly believe Libby and Hannah will receive a mercy they might not even have a cognitive awareness that they need. That changes everything, even the perspective of cruelty in suffering.

Additionally, I have learned a fundamental and foundational gospel-truth by navigating our own story of suffering. The subtitle of this thesis is "A Father's Perspective on the Theology of Suffering," and as it relates to suffering, I have shared a great deal of my perspective based upon my family's experience. I would, however, be remiss if I did not remind the reader that I am only one broken father telling of *my* perspective. The power and majesty of the gospel reveals a perfect heavenly Father who has a perfect perspective on suffering. My girls have suffered, and I have watched through broken lenses, but God the Father watched His only Son suffer and He witnessed it with perfectly clear vision. Authors Tada and Estes explain,

God, like a father, doesn't just give advice. He gives himself. He becomes the husband to the grieving widow (Isaiah 54:5). He becomes the comforter to the barren woman (Isaiah 54:1). He becomes the father of the orphaned (Psalm 10:14). He becomes the bridegroom to the single person (Isaiah 62:5). He is the healer to the sick (Exodus 15:26). He is the wonderful counselor to the confused and depressed (Isaiah 9:6).

This is what you do when someone you love is in anguish; you respond to the plea of their heart by giving them your heart. If you are the One at the center of the universe, holding it together, if everything moves, breathes, and has it's being in you, you can do no more than give yourself (Acts 17:28).³⁹

This reality of God's only Son, Jesus, enduring great suffering for the sake of others, makes faith in Christ and the power of the gospel so significant. Keller explains, "So, while Christianity never claims to be able to offer a full explanation of all God's reasons behind every instance of evil and suffering—it does have a final *answer* to it. That answer will be given at the end of history and all who hear it and see its fulfillment will find it completely satisfying, infinitely sufficient." Christians trust what God sees perfectly when they only see dimly, rest in what God knows infinitely when they only understand partially, and hope in what God has done finally, when they only think temporarily.

Dave Furman offers a similar summary explanation when he writes,

In the same way Christians should never get over the incarnation of Jesus. It is surprising that God would come to us. When we are walking through trials of various kinds, we need to remember this truth. God did not leave us alone in this world. The Son of God left heaven and came to earth. He faced incredible pain and suffering himself to rescue us from our sin and bring us hope in our trials.⁴¹

God knows suffering because, as seen over and over again, God endured suffering; the worst suffering, and he did it for His people to be saved.

Of course, beyond simply navigating and understanding God's empathy in suffering, as one who has suffered in the most significant way, many sufferers continue to struggle with this question of how God can allow suffering to happen to the "innocent."

³⁹ Tada and Estes. When God. 125.

⁴⁰ Keller, Walking with God, 158.

⁴¹ Furman, Kiss the Wave, 42.

Therefore, I will address that struggle because it is important. Suffering only happened to the truly innocent once. The power and majesty of the gospel is that God has done for His people what they could not do for themselves because He undeservedly took upon Himself that which was rightly owed to them as sinners.

I love the way Joni Eareckson Tada expresses the gospel reality of God, the innocent, suffering for humanity, the guilty, when she writes,

When I think of all this, it strikes me that these limitations didn't just "happen" to Jesus in the same way that circumstances "happen" to you and me. The amazing thing is that Christ *chose* to be handicapped. I can't think of too many people who would actually choose to be disabled. Believe me, I know I wouldn't! There is nothing easy, nothing fun, nothing casual about dealing with a disability. From the very get-go, it's *hard*.

But Jesus chose to handicap Himself so that you and I might share eternity with Him in bodies that will never stoop, limp, falter, or fail. Jesus chose to experience pain and suffering beyond our imagination in order that you an di would one day walk the streets of heaven whole, happy, and pain free. Jesus chose to die—though that was a daunting task in itself. As C.S. Lewis wrote, Jesus "was so full of life that when He wished to die He had to 'borrow death from others.'"

But borrow it He did, taking it unto Himself, yielding up His life, so that you and I might pass through death's shadow and live forever.

Yes, while I'm alive here on earth, I am called to endure a handicap. But how could I be other than grateful and content? I'm in the best company of all. 42

It is a breathtaking reality for Christ-followers when this grace begins to set in and resonates in their hearts.

Jesus was and is innocent, but He died like the guilty. Hebrews 4:14-15 reads, "Since then we have a great high priest who has passed through the heavens, Jesus, the Son of God, let us hold fast our confession. For we do not have a high priest who is unable to sympathize with our weaknesses, but one who in every respect has been tempted as we are, yet without sin" (Heb 4:14-15). I understand wanting to argue for the innocence of someone who is young, especially a baby, a small child, or someone with a cognitive disability like our girls. I get it, I have done it, and it makes sense to me.

However, that argument is a misunderstanding of genuine innocence. Genuine innocence

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⁴² Tada, A Place of Healing, 239-40.

is to be without any wrong, to have complete and perfect purity. And no person, regardless of age or ability, can lay claim to that, except Jesus. The Bible says that sin is in the nature of every person, inherited from Adam: "Therefore, just as sin came into the world through one man, and death through sin, and so death spread to all men because all sinned" (Rom 5:12). But, Jesus was not from Adam. He was divinely conceived by the Holy Spirit, directly given to Mary and therefore He escaped the nature of sin that plagues the rest of humankind. What is more, not only was Jesus born sinless, but He lived sinless. He was perfect, and yet died as though He were not. He died for us: "For our sake he made him to be sin who knew no sin, so that in him we might become the righteousness of God" (2 Cor 5:21).

Alcorn explains the wonder of God's amazing grace:

It's one thing to suffer terribly, another to *choose* to suffer terribly. Evil and suffering formed the crucible in which God demonstrated his love to mankind. What is good about "Good Friday"? Why isn't it called "Bad Friday"? Because out of the appallingly bad came what was inexpressibly good. And the good trumps the bad, because though the bad was temporary, the good is eternal. God's love comes to us soaked in divine blood. One look at Jesus—at his incarnation and the redemption he provided us—should silence the argument that God has withdrawn to some far corner of the universe where he keeps his hands clean and maintains his distance from human suffering. God does not merely empathize with our sufferings. He actually suffers. Jesus is God. What Jesus suffered, God suffered.⁴³

When suffering is cruel, sufferers should be reminded of the cruelty of the cross—the only place in all of history where the innocent truly suffered. And in His suffering, for the sins of all, He made a way for suffering to end, forever. Suffering is real, and suffering can be cruel. Call it what it is and give thanks and praise to God through Christ who has overcome it all.

⁴³ Alcorn, If God Is Good, 209.

CHAPTER 4

COMPLETED THROUGH SUFFERING

In this chapter, the redemptive thread of suffering will continue to be explored. Using my daughters, Libby and Hannah, as the continued testimony, this chapter will give an honest explanation of how God continues to shape our family's theology of suffering, as well as opens doors for ministry opportunities, which are desperately needed for others navigating the choppy waters of suffering. Finally, the reader will be challenged through self-examination and extended a personal encouragement to (1) endure well current challenges; (2) reflect appropriately on past challenges; or (3) ready themselves in grace toward the challenges that are sure to come.

Complete

My family has developed a tradition around the family dinner table at our house. It has honestly become one of my favorite things that we do as a family. In an effort to engage our kids in conversation beyond the usual "How was your day?," followed by a series of grunts and eye rolls, and for that conversation to be as redemptive as possible, with everyone required to participate, most nights we play a game called "Pit and Peak." The premise of the game is simple. Every person shares the worst part of their day (the pit) and then the best part of their day (the peak). Each person can give as much detail about each part as they wish and everyone else is invited to ask questions, celebrate victories, or offer words of encouragement if and when they are needed. It is usually lighthearted, gives plenty of fodder for teasing and picking at one another, a lot of fun, and an easy way for us to navigate dinner conversation easily, but on more than one occasion it has included tears.

Our youngest daughter, our six-year-old Campbell, loves to pick the batting order and make the rules as to who goes first and who goes last. Sometimes she says youngest to oldest, other times she says smallest to tallest and occasionally she mixes it up with a random order, that only she gets to decide. Any way you slice it, she is always going first. Additionally, we mix up our "Pit and Peak" game by adding mandated accents to be spoken by each person as they are describing their personal pits and peaks of that day. My personal default is a British accent, of which I am quite proud. Our daughter Kathryn will usually draw on that one as well, while my son Coleman almost always chooses to travel a little further south and brings a terrible Australian accent to the game. Campbell does not have any accents yet, her best attempts are simply to raise the volume of her talking, and Mary is a party pooper and usually refuses to attempt any accent at all. It is a wheels-off, yet fun few minutes around our dinner table, but there is always laughter, and everyone gets to share. We are each invited, if only for a few minutes, into one another's world for the best and worst parts of that particular day.

In this chapter, I am going to invite the reader to dinner with my family, but instead of playing "Pit and Peak" traditionally, I have asked several of family members to simply share their own thoughts, feelings, experiences and struggles from the journey we have been on with our girls. Given the uniquely personal nature of this thesis, and in the absence of empirical research, personal testimonies have been provided within this chapter. They will provide a detailed testimony from the perspective of immediate family members. Hearing from each of these individuals will be helpful and might give a broader and clearer picture as to how God has used, and is using, our girls to impact, change, shape and bless our lives. Going in an order from tallest to smallest, I am up first.

Family Experiences

My Experience (as Father)

It is difficult to explain all the ways my girls, Libby and Hannah, have impacted my life. I do not know if I can do justice to the deep desire I have to speak of the blessings

my girls have brought me. I have given the majority of this thesis to explaining the hardship that comes with their suffering, but it would be entirely incomplete to ignore the incredible ways I have experienced and am still experiencing the grace of God through the lives of these two little girls. However, I will give five thoughts on what I have seen God do thus far.

First, I am aware that each day we have with these girls is precious. In this fast-paced world of always looking toward what is next, I have grown more keenly aware of the treasure and the gift of life. Because all life is created by God, this new appreciation for the value of life, brevity of life, and joy that comes in life help stir my affections for God as a worship-inducing byproduct. All parents would agree that all days with all children are precious, but given the original prognosis of losing our girls by the age of two, and yet for no reason other than God's grace still having them today, it makes our time together so much more valuable and cherished. Each day with them is a gift. We are living on borrowed time, but borrowed only from our doctors and not from our God.

Second, the journey with our girls has deepened my trust in the Lord and therefore strengthened my prayer life with the Lord. I have not always been a disciplined person. I have not always maintained discipline in my physical health (i.e., diet and exercise) or in my spiritual health (i.e., prayer and Bible reading). Though just like when a doctor gives a dire prognosis if ones health does not improve, mandating radical lifestyle changes to promote it, in the same way God can use trials and suffering to motivate radical spiritual changes in the life of sufferers as well.

I have found that because of the rarity of our girls diagnosis and subsequently all of the unknowns that come from treating the symptoms and complications that result from it, I have been forced to rely upon the Lord for grace, healing, and supernatural provision, where medicine and men were unable to ease my angst. Do we still use medicine and glean the wisdom of man, yes absolutely! But, are we finding ultimate comfort in what that will provide our girls in the end, no, absolutely not!

I am challenged by the honest words of author Mark Vroegop, when he writes,

I wonder how many believers stop speaking to God about their pain. Disappointed by unanswered prayers or frustrated by out-of-control circumstances, these people wind up in a spiritual desert unable—or—refusing to talk to God. This silence is a soul killer. Maybe you are one of those who have given God the silent treatment. Maybe you just do not know what to say. Perhaps there is a particular issue or struggle that you just can't talk to God about. It feels too painful. I hope you will be encouraged to start praying again. Or perhaps you have a friend who is really struggling in grief. Maybe this person prays some things that make you uncomfortable—even wince. But before you jump in too quickly and hush his or her prayer, remember that at least your friend is praying. It is a start. Prayers of lament take faith.¹

When the doctors do not know what to do and the outcome seems bleak, prayer has been the greatest treatment plan I have been prescribed. Libby and Hannah have taught me to pray with reckless abandon. They have taught me to forsake the insecurities of how it might look to pray when we begin a meeting at our local public school about the girls' educational plan, in a pre-op waiting room handing off to anesthesia, in an ambulance on the way to Dallas, in the middle of the night when they cannot tell us what hurts, or at a laboratory when after four failed attempts they still cannot find a vein. My girls have taught me that I can call out to God in prayer anytime for anything. They have taught me to pray when everything is going wrong and when everything is going right, when they are sick and the outlook is grim, and when they are healthy and thriving in their daily routine. God has used the girls to deepen my trust of Him and has granted me the desire for more prayer conversations with Him.

Third, the girls have forever shaped our family, for the better. I am blessed to watch Mary up close as she serves our girls tirelessly and selflessly on a daily basis. She always meets their needs before her own and tends to their personal care and well-being in the most Christ-like way. As a testimony of how God uses my bride, I cannot tell you how many doctors and nurses have commented on the girls generally good health or their exceptional hygiene or their joy and contentment, and each compliment it is almost always

¹ Mark Vroegop, *Dark Clouds, Deep Mercy: Discovering the Grace of Lament* (Wheaton, IL: Crossway, 2019), 32-33.

loaded with great surprise and appreciation. Because special needs persons are often challenging to care for, much of the care they receive is not always great. Tragically, this is what many doctors and nurses are more accustomed to seeing. But not our girls, and my Mary is responsible for that. She is a champion, truly.

Our other three children, Kathryn, Coleman, and Campbell have also been greatly transformed and shaped by our girls, their sisters. Watching each one love on their sisters in ways that are unique and special to them blesses me as the dad to all five in ways that are tough to describe. I am choking back tears as I think about how Kathryn cares for Libby and Hannah like a maternal nurse, with instincts toward love and care that are obviously gifts from the Lord. She is also is fiercely protective of both girls in the most incredible ways, and I love that she will not tolerate anyone being rude or unkind to them. Kathryn has been exposed to some of the worst parts of our journey, including a few of our most challenging moments with these girls, and I am grateful that Jesus has used those events to shape and mold her into a gospel warrior for the marginalized, helpless and often overlooked in the world.

Coleman too has been shaped into a fiercely loyal protector of his little sisters. He is an unbelievable servant who is constantly running to grab things we have forgotten and/or to wipe the drool from their mouths or help unload and setup their wheelchairs, all while moving ahead with our family rhythm and schedule. Coleman is adamant that these girls be as much a part of "normal" as anyone else's siblings might. Coleman is sensitive to protecting the girls' dignity and he is very playful with both sisters as only a big brother can be.

Campbell has also been a joy to watch engage with Libby and Hannah. She will tell you, if you ask, that Hannah is her best friend. They grew up like babies together and Hannah was actually in a baby crib longer than Campbell, so they are naturally very close to one another. Campbell still gets in bed with her sisters to watch YouTube videos of Mickey Mouse or to play the *Frozen II* soundtrack and sing along or to watch *Shrek*

and laugh out loud at all of the inappropriate bodily noises celebrated throughout the film. She has slumber parties in the bed with Hannah and will stay up talking to them both. She has never known life apart from these two girls, so everything for her is normative, including the hundreds of doctors' appointments she has gone to with us. Campbell thinks her sisters are awesome and she would not understand it if anyone did not. I am grateful for this innocence and believe everyone could benefit from a little more of Campbell's perspective on those who seem different from ourselves.

My family has been forever shaped in the most positive ways by Libby and Hannah, and Libby and Hannah have been forever shaped in the most positive ways by our family. I would have never known how God was going to use the Bales family dynamic to mold each one of us individually into who He created us to be together, but it is a joy to watch unfold.

Fourth, I am grateful to God for the ways He has used our girls to shape our extended family and friends. My brothers, Jayson and Neil, each have a close relationship with their nieces for different but special reasons. Libby likes that Jayson has always held her and talked with her and made her a priority to him. Hannah likes Neil's beard and that he does not mind if she pulls it or tries to eat it, because it is a sensory toy to her. Likewise, their spouses and children are all incredibly kind to our girls. When our extended families get together, on both sides of our family, our girls are right in the thick of things and everyone is taking turns holding them and talking to them and teasing with them. They are just a part of our family dynamic and I credit our entire family for their Christ-like acceptance and love of Libby and Hannah. Our parents have also been a tremendous blessing to us. Watching them change and grow through the experiences they have shared with their granddaughters has been a joy to see. Our parents have been very supportive, clocking hundreds of hours of babysitting during hospital stays and offering hundreds of hours in prayer, asking for God's provision for their lives. I am grateful for how God has shaped our family through the gift of our girls.

Our friends too have been forever changed by Libby and Hannah. Watching other families, who may or may not have much experience with individuals with special needs, engage and love our girls is so much fun for me. I love seeing how our girls are talked to and treated in the most normal way by other moms and dads and kids who love them because they love us. I have also seen God use our girls to broaden many of those families' understanding and appreciation for disability ministry, including using our girls' story as a catalyst for founding and funding that ministry in other settings for other people. Many of our friends have displayed patience with us as we move slower when we go out to eat or on a vacation. Many friends have stood watch during prayer vigils, given hours and hours in hospital visitations, thousands and thousands of dollars, and dozens and dozens of meals, all in the name of Christ's love for our family, because God used our girls. Paul Tripp beautifully summarizes this gift of biblical community when he writes,

Yes, it's true that the God of all comfort sends his ambassadors of comfort into your life. They are sent to make God's invisible presence, protection, strength, wisdom, love, and grace visible. So welcome his ambassadors. Be open to their insight and counsel. Confess your needs so that God's helpers can minister to those needs. Live like you really do believe that your walk through hardship is a community project, and be ready for the good things God will do.²

The church is nothing short of a gift of God's grace to and for sufferers. God has never intended for his people to endure hardship in isolation. Our family has benefited from the strength and blessing of community and I am forever grateful for it.

Fifth and finally, I am forever grateful to see how God has used our girls to shape our churches. From the church we attended when Libby was born, who filled the hospital surgical waiting room during heart surgery and have subsequently added a vibrant special needs ministry to serve other families like ours, to the church where I first served on staff and where I serve again today, which had a vision for special needs ministry before it was as widely accepted and as understood as it is today. Our church

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² Paul David Tripp, *Suffering: Gospel Hope When Life Doesn't Make Sense* (Wheaton, IL: Crossway, 2018), 201.

was on the forefront of this gospel ministry and our family has been and is being shaped by the influence it has on us and so many others even now. And as for our church in East Texas, this body of believers was literally the hands of feet of Christ to us during the worst moments of our life. They stood watch and in the gap in so many ways that cannot all be recounted. This church has a vibrant special needs ministry on both of its campuses today and hundreds of people are impacted either by the ministry as recipients or through the ministry as servants. God has broadened in each one of our church families a perspective on suffering and the kingdom of God. I am humbled and honored that He has used Libby and Hannah Bales to do so much of it. These are just some of the blessings the girls have brought to me!

Mary Bales' Experience (as Mother)

As I think about my journey with the Lord, there are a few defining moments.³ There are moments when I know that the Lord was present. That He was working in our midst. Honestly, most of these moments occur after a season of great confusion and feelings of abandonment—this is how I would describe the first few months of Libby's life. In the beginning I was confused, sad, and doubting. How could God do this to our girl? What was He up to? How was I to respond to this "new normal" when everything felt so abnormal? I was angry. I looked around and thought that we had done everything right. We had surrendered all to Him and now we were walking through this unbelievable suffering. I remember thinking, "We are not the special needs family—this does not define us," and that was true. I tell people all the time that our family had a story before Libby and God has only continued that story. However, we *are* a special needs family. I remember clearly surrendering to this. It was not easy. I remember thinking, "Okay, God... this is where the rubber meets the road." This is where I have to truly decide if I believe all that I said I believed before we were thrown this massive

³ All text in this section is by Mary Bales.

curve ball. Is God good? Is He sovereign? Is He loving? Can I trust Him? The short answer to all of those questions is "yes." I never want to minimize the process that led me to that answer. He has been so faithful. He has used His Spirit, His people, and His Word to move me to this answer.

I cannot count the number of times that I have heard God speak to my spirit, reminding me that He is there. Reminding me who He is and who I am, in Him. He has prompted me to serve others who are in the ditch. He has convicted me to be patient for those who are grieving. He has encouraged me to walk in my calling as a wife and mother

I cannot count the number of times that I was in the ditch and, with patience and great care, someone has come to sit beside me, in the ditch. Someone was patient while I grieved and processed. God has used His people to love and minister to our family in ways that we can never repay or express. We have been prayed for, fed, visited, and loved in so many countless ways. Our community of believers has always stepped up. We have had a rare glimpse of the church at work. Since we lived in the Dallas area for twelve years and then moved to East Texas, we had the beautiful picture of our local churches working together to love and serve us. Every time we were sent to Dallas for a hospitalization, the church in east Texas was there to pray us off and provide for those in our home. When we arrived at the ER, the church in Dallas was there to greet us, praying and providing for our needs while in the hospital. The church and her fellowship are a beautiful piece of our story.

God's Word—wow. I think about my journey before the girls. My limited understanding of God's ability to speak and move and act. I read stories in the Bible and wondered if He would do the same for me. As Connor shared about our study of John 9, God also engraved a Scripture on my heart, and it has become my life verse. You probably will not find it on a coffee mug, but the truth of it has changed my life. John 16:33 says,

"I have said these things to you, that in me you may have peace. In the world you will have tribulation. But take heart; I have overcome the world."

As I think about this verse, I am grateful for all that He has taught me. In this world, broken and fallen, we will have tribulation. He never promised us an easy life, He never promised that life in Christ was easy. One only has to read the New Testament to see the lives of His disciples. I began to wrap my mind around the fact that I had a terrible theology of suffering. I believed that my faith and my dedication to the things of God would exempt me from the brokenness of this world and the brokenness of my family. When I began to see that no one is exempt, I could begin to try to understand where hope is found.

Believers have an eternal hope that Jesus has come to deliver us into right relationship with God. He has overcome the world—that means everything that you and I go through, He has already overcome it. We have not, and that is why there is grief and pain, and why we are angry and sad. Sometimes we can feel overcome by our grief, sadness, anger, and questions. I have learned that God can handle all of that. So many times we try to fake it with God. We are surrounded by pithy statements and terrible theology that says, "God will never give us more than we can handle," or "If you have enough faith, healing will come." God always gives us more that we can handle because He loves us enough to engage in our suffering. I am encouraged by what Randy Alcorn writes:

Suffering is limited. It could be far worse. Suffering is temporary. It could last far longer. Suffering, as we've seen, produces some desirable good. It can make us better people, and it can reveal God's character in ways that bring him glory and bring us good. God can see all the ultimate results of suffering; we can see only some. When we see more, in his presence we will forever praise him for it. He calls upon us to trust him and begin that praise now.⁴

⁴ Randy Alcorn, *If God Is Good: Faith in the Midst of Suffering and Evil* (Colorado Springs: Multnomah, 2009), 488.

This idea of trusting God in the midst of this present unknown is difficult, but so necessary.

This is where the believing sufferer finds absolute freedom.

Second Corinthians 1:9 says, "Indeed, we felt that we had received the sentence of death. But that was to make us rely not on ourselves but on God who raises the dead." He wants us to rely on Him. So, slowly, over time, I began to rely on Him. When doctors could not give adequate answers or explanations, I began to rely on Him. I began to trust His Word. In His grace and mercy, through some of the most painful and difficult circumstances in my life, He softened me. He was there—he was patient, loving, and consistent. His Word taught me that there is nothing that I will ever experience that He has not already overcome, on the cross. So, whatever it is—a financial woe, broken relationship, devastating diagnosis—He has overcome it all. This does not dissolve the pain, anger, and sadness, but it does refocus my thoughts from fear to praise, thanking Him for overcoming all that I cannot. When I feel overcome by emotion or circumstance, I am thankful that He is not. He defeated those things when He went to Calvary. I have learned that He is big enough to handle my grief. I can cry out to Him, I can question and doubt, I can be angry and tell Him about it—He already knows. Why do we try to fake it? He is so big, and all of our emotions are acceptable to Him. He wants us to rely on Him. How can I rely on Him when I am not honest with Him?

So, remember when I said that "the rubber met the road"—this was a beautiful time where I felt the Lord's presence and peace. He gently guided me and was patient with my immaturity. He showed me that it is in the valley where we need the Shepherd the most.

Kathryn Bales Experience (as Sister)

Our oldest child, Kathryn, is sixteen and the most incredible older sister one can imagine. I am so proud to be her dad. Kathryn is a Christian and fiercely protective of our family. I have asked her to share her experiences and learning, by having two sisters

with severe special needs. I believe any fellow sufferer will be blessed learning from her honesty.

Having Libby and Hannah as sisters has been a very challenging but also, incredible experience. ⁵ They have each taught me something different that I would like to share. One thing I have learned from having Libby and Hannah in my life is compassion and tenderness. This was revealed to me in the pit of 2018 when Hannah was ill. When Hannah was first prescribed the new seizure medicine, which created all her complications, I was very angry. I thought that the doctors did not care about her and that she was "just another patient." As her medicine started to kick in, her emotions took a turn for the worse and her health was only declining. She was not only having seizures, but she was sleeping all the time and was rarely smiling. She was still Hannah, but she was not my Hannah as I knew her to be. As I saw a decrease in her health, I neglected to see a change in my attitude, but it was obvious to everyone, except me. I was no longer just angry at this point, I was now infuriated. One day, this all changed. In March of that same year, she crashed. My mom was out of town which made things even harder on our family because she is our balance among all the chaos. However, with my mom not there, my dad asked me to go with him to the Emergency Room. Not knowing the emotional toll it would take on me, I agreed. When we were in the car, I was sitting in the front with my dad while Hannah was in the back. But during the drive, Hannah was so unstable that I climbed in the back to make sure she stayed awake. When we got to the hospital, I was terrified. We rushed Hannah in only to hear, "Mr. Bales, this is bad you might need to call your wife." I was at a loss for words. Watching Hannah struggle to breathe right in front of me killed me. I wanted to do something but there was nothing I could do but sit, watch, and pray. While the doctors struggled to get Hannah intubated, I was in the hallway calling my neighbor and my mom, struggling to get out my words. The nurses

⁵ All text in this section is from Kathryn Bales.

and doctors moved Hannah from the regular patient room to trauma because she was still not intubated and she was struggling to breathe. After she had been in the trauma room, an emergency room doctor who is also a close family friend, came in from his son's soccer game (in street clothes) and was able to get Hannah intubated. After he got her intubated there was a more assured hope for her life. The doctors still insisted her be care flighted to Dallas' Medical City, as soon as possible. With this in mind, my dad had a family friend come and pick me up from the ER and take me home. I was scared, not knowing if I was going to see Hannah again. After multiple days of prayer, fear, and love from friends and family, there was less of a fear for Hannah's life. I was still emotional, but was able to focus more clearly and serve my family as much as possible. With Hannah in the hospital and my parents there with her I felt lonely; I missed being with my whole family. She was in the PICU for five weeks, but it felt like an eternity. After that five weeks when Hannah came home, I noticed a change in myself. I was not angry anymore. I got to peek behind the curtain just enough to see that the doctors were not giving up on her, and that she was not "just another patient." The love that the nurses showed her was unbelievable, and the way the church family ministered and blessed our family was so generous and overwhelming in all the best ways. Hannah going through such a tough season of suffering showed me the love of God and how he is so gracious to us. Because of my sisters I am more compassionate and tender.

Not only have they taught me tenderness, but they also taught me to be aware of my surroundings. Like my brother, I will never let a door shut on anybody, because of the numerous times I have run ahead to grab the door for a wheelchair. Not only that, but I have a bit of a scrappy personality and that is easily seen if people are making fun of others, especially those who cannot stand up for themselves. I do not like it when people use the words "retard" or "retarded" as a common "funny" adjective to describe their friends. My sisters have allowed me to see that everyone has equal value and not one person should be degraded, no matter what may be going on in their lives.

They have also shown me how to love the least of these. I have the amazing opportunity almost every year to serve at a camp for families with disabilities and be a one-on-one camp counselor for a child with a disability. I count it one of my greatest blessings to see people with special needs or disabilities treated as though they are kings and queens and loved on constantly. It is truly a glimpse of heaven in the way people are loved, served, and cared for the whole week long.

Not only have the girls taught me these things, but they have also been able to give our family many blessings. Because of the girls, we get a handicapped parking space, which seems like a small and insignificant thing but when you have 4,000 things to carry and 5 kids to manage, it makes the world's difference to our family. Not only do we get handicapped parking, but because of Libby and Hannah we have been able to go to Disney World for Libby's Make A Wish trip, and we went to Disneyland for Hannah's. This has been such a tremendous blessing and would have never been possible without Libby and Hannah. Libby and Hannah have made such an incredible impact on my life and I am extremely grateful to call them my sisters.

Coleman Bales' Experience (as Brother)

Our second child, Coleman, is thirteen and the most incredible brother and young man. I am so proud to be his dad. Coleman is a Christian and fiercely loyal to our family. I have asked him to share his experiences and learning, by having two sisters with severe special needs. I believe any fellow sufferer will benefit by his transparent tenderness as he shares how he has grown through navigating life with Libby and Hannah.

Life with Libby and Hannah has been like one big roller coaster.⁶ There are some highs and lows, but through it all God has shown me many things. Like for

⁶ All text in this section is from Coleman Bales.

instance, tender-heartedness. If a door is closing, I never let it close on anyone because of all the doors I have opened for our wheelchairs.

One of the peaks in my life came out of one of the pits. It happened as a result of Hannah's suffering in 2018, when I came to the realization that I was not saved. When Hannah crashed, I was walking the walk, and I was praying and doing all the right things, but Hannah kept declining. I thought that Hannah was being punished for something that I had done. So, I prayed more and more and harder, but still there was no increase. When she finally got better, I thought, "ok you didn't mess up and Hannah got better." But then that October she went back to the hospital and was there for about two more weeks. The feeling came back, but yet again she came home. December rolled around and December 5, 2018, God decided to write a story through my life. That night my life was forever changed. I accepted Christ and I did not see why or how something good could come out of Hannah's situation but that December night I saw clearly why that bad feeling was there. I was praying to a God I knew about but did not know on a personal level and had no saving relationship with. Now I am eternally grateful that God used an awful situation in my life to turn me from dark to light.

Another peak from a pit is that God has shown me how to persevere. I love running; it has become something I really enjoy. But I do not run short races, I do the 800m and up. I love the distance. And in distance running, especially the 800m, you are basically sprinting for half a mile, so endurance is crucial. What I have learned is not about physical endurance but mental and spiritual. I learned most of this endurance during the crash phase, that went on for about 8-10 weeks. Not knowing the outcome, if your little sister will live or die, is suspenseful. I can remember nights where I would stay up and hope that I would see either my mom or dad coming home from the hospital, and that was the hardest race I have ever run and probably ever will.

But some peaks are that we got blessed with the opportunity to go to both

Disney World and Disneyland through Make A Wish. This was such a blessing because

we had spending money and a place to stay and a "genie pass," which if you do not know, gets you to the front of the line immediately. But the biggest blessing was the Disney World staff. They went out of their way to make us feel welcome and special. Several invited us to private rooms and special quiet rest stops. And that makes you see that the world has good people, you just have to look harder for them. That is both my pit and peak of life with Libby and Hannah. P.S. My Australian accent is amazing!

Campbell Bales' Experience (as Sister)

Our youngest child, Campbell, is six years old and the most wonderful little sister in the world. I am so proud to be her dad. Campbell is growing in her understanding of faith and learning daily what it means to trust in Christ. She is passionate about our family and knows no life without her older sisters, and all the challenges that accompany it. I have asked her to share her experiences and learning, by having two sisters with severe special needs. I believe any fellow sufferer will be blessed learning from her innocence and joy.

Libby and Hannah have taught me to be so crazy!⁷ The girls like to laugh and they like funny noises. I like to have sleepovers in their room and I really like to cuddle with them. I like to watch movies in their bed, mostly Disney. I like to wrestle with Libby and I really like to push Hannah in her stroller.

I have learned how to help my mom and dad with my sisters. I can help with bath time, I can unhook their feeding tubes after they've eaten. When the girls are sad, I know how to make them happy. I know which toys are their favorites. God has taught me to be kind in different ways and when God sees the girls, I think He thinks they are perfect.

⁷ All text in this section is from Campbell Bales.

Sallye Bales' Experience (as Grandmother)

In an effort to offer a multi-generational family perspective, I asked both maternal grandmothers to share their experiences with Libby and Hannah as well. My mother, Sallye "Granny," is a Christian and fiercely devoted to our family and a selfless servant. I asked her to share her experiences and learning, by having two granddaughters with severe special needs. I believe any fellow sufferer will be blessed learning from her honesty and redemptive hope.

After I heard that Connor was writing this thesis and that Libby and Hannah's brother and two sisters were going to be able to express their experiences to this amazing story, as siblings, I asked Connor if I could contribute a grandparent's perspective of my relationship with the girls. He graciously allowed me to share what I call "my view from the top." By that, I mean when you walk the journey of climbing this life's mountain, you reach the top of that mountain, when for some of us, becoming a grandparent occurs. We think of that age as being filled with experience and hopefully God's wisdom, that has been gained throughout the journey.

When we became grandparents, neither Granny (me) nor Granddaddy (my late husband) were prepared for having two special needs granddaughters. Our journey with the "view from the top" had not included that. Neither of us had even been around others who did not have the capacity to walk and talk. In the midst of our broken hearts over this new reality was the question, "Why, Lord?" Then, fear followed, as our flesh was tempted to think of the uncertainties and heartbreaks ahead in the lives of these beyond adorable, sweet, and totally dependent granddaughters.

However, it did not take us long to move past that fear, and Granddaddy was soon cuddling and singing lullabies to each of these precious girls whenever we babysat. I learned to hook-up feeding tubes and the two of us saw how God was using these

⁸ All text in this section is from Sallye Bales.

experiences to grow us and expand our horizon, in yet another area of our lives. Very quickly we realized that "Libby's world and Hannah's world" are indeed special places! Each place is filled with response, personality, and charm that is unique to Libby Faye and equally unique to Hannah Jane.

Their Granddaddy has gone home to be with Jesus now, and I know he will be lovingly waiting with arms open wide whenever these two girls, who are gifts from God placed right in the middle of the Bales bunch, are one day home with Jesus as well. At that time, I can predict that Granddaddy Bales will have tears of joy as he sees Libby and Hannah walk and talk! Some of my favorite family picture memories include Granddaddy holding these two wonderful girls, whom he deeply connected with.

As I continue to lift both Libby and Hannah up to God for healing, I no longer ask "Why, Lord?" Now, I say, "Thank you, Lord!" I have the blessing of seeing God's strength in Connor and Mary. I see God's support in Kathryn, Coleman, and Campbell in how they love their sisters. I see God's compassion in the Bales aunts and uncles and cousins. These are precious treasures that a mother and grandmother ponders deeply in her heart. My spiritual journey that has led me to my "view from the top" has forever been blessed and changed by two angel girls who do not yet walk and talk, but will!

Ellen Pollard's Experience (as Grandmother)

Likewise, my mother-in-law, Ellen "Mimi," is a Christian and a proven, compassionate friend. I asked her to share her experiences and learning, by having two granddaughters with severe special needs. I believe any fellow sufferer will be blessed learning from her kindness and thoughtful reflections.

When Libby was born, Mary and Connor knew right away that there was a problem. She had a hole in the heart and would need open heart surgery. This was

⁹ All text in this section is from Ellen Pollard.

devastating news but not the worst to come. Her heart was fixed, and for a moment, ours were as well. We thought all was good. As months went on, it became evident that there were other problems. Libby was diagnosed with Trisomy 16P.

Dealing with this, Libby's personality was emerging. She knows what she wants and definitely what she does not want and lets you know both. I learned early that Libby understands what you say. I was with her one time and I said," Roll over here and Mimi will pick you up." And she did! She came right over to my feet and I picked her up and we were both happy. I was afraid that she would forget who I was as I am not always there, but she never forgets people. She knows voices. When I come to the house, I can hear her squealing in her room. She wants to see me. Libby loves to be hugged and can give great hugs as well. She likes to play "rough." In fact, after spending time with Libby, others in the family will say, "Oh, you've been to the Libby salon," as she likes to mess up your hair. She does not care for therapy and sometimes does not like school. She is social up to a point but then loves being in her bed. She has favorite movies and songs. I remember one time she helped Mary plan her birthday party by shaking her head yes or no depending on what she wanted. She has learned to say a few words—Mom and Dad. How precious is that? I am working on getting her to say Mimi. Libby is an amazing little girl and has spread so much joy! People want Libby to like them and they try hard to make that happen. I love Libby more than I can say and I know she loves me too!

Hannah has the same chromosome disorder as Libby even though when Mary discovered she was pregnant, the doctors said this would never happen. The disorder is very rare and to have two in the same family just would never happen. But it did! But Libby and Hannah are as different as night and day. Hannah is pretty much always happy and loves being with people and being held. She loves sitting in her special chair and loves therapy and loves school. It is hard to believe that one disorder can have such different effects on both girls. Hannah is the more fragile of the two. She has had many medical issues—mainly pneumonia. Mary and Connor could both be medical doctors as

they know what to do when something goes wrong. They have found a team of wonderful doctors who work well with them. Hannah is so sweet—all still call her sweet little Hannah even though she has grown a lot! She will always be our sweet little Hannah! Hannah smiles most of the time and chatters away. She can say Mama! I am working on Mimi with her too!

These are my special and special needs granddaughters. They have taught me to love more than I thought I could. They have taught me to appreciate the small things like a smile or a hug. When either girl starts laughing it seems the world laughs too. Hannah knows how to clap at appropriate times. This has been a joy. They make me and so many others so much happier just by being who they are. I love how they have set the family dynamics. Campbell (age 6) has grown up saying that Hannah is her best friend. Kathryn (16) is now talking about becoming a surgical nurse. Both Kathryn and Coleman (13) can do most things for the girls. They can hook and unhook the feeding tubes and do many other tasks too. Kathryn can lift and carry both girls. If either girl is unhappy, Coleman is often sent in to cheer them up. Life can be so difficult but often it does not have to be. The girls have taught me to take a breath and just enjoy the moment. If I have had a rough day, I stop and think of what kind of day Libby and Hannah have had. Even though they are so restricted by what they can and cannot do, they are still happy. I have no right to complain. They are our special angels put on earth and given to this wonderful family to show us all that we can be better people. I remember this often and I do try. Thank you, Libby and Hannah.

Some days I wish Libby and Hannah could be like every other eight and eleven-year-old, but then we would miss the Libby and Hannah we have. And as their Mama always says, "You are just perfect!" And they are!

Concluding Thoughts

Finally, I want to close this section by sharing one last blessing that life with our girls has allowed us to enjoy. I would summarize this blessing as a little bit of heaven

on earth. As I have mentioned, our girls have given our entire family, extended family and our friends, a passion for special needs ministry that I am confident we would not have, except that God placed Libby and Hannah in our family. One of the most wonderful examples of this type of ministry is the amazing life work of longtime disability advocate Joni Eareckson Tada. Since having Libby, Mary and I have only grown in our passion for and blessing from disability ministries, like the one founded by Joni, called Joni and Friends. As we have learned more about her vision and passion for Christ and its translation into working diligently for decades to serve others with disabilities in His name, Joni has become a hero to me and my family, and is someone we look up to and deeply respect.

Stephanie Hubach offers one of the most helpful summaries of disability ministry that I have found, when she says,

Disability ministry can be understood as a pro-life ministry in the fullest sense of the term. Engaging the lives of individuals and families who are touched by disability shows them that the church is *for* their lives—honoring the image of God in each and every person. Having a vison for special needs ministry that is deeply rooted in the sanctity of human life—in all of its diversity—can be quite energizing. When we realize that those upon whom God has stamped his indelible image are being trodden underfoot by dysfunctional social systems, it should stir our hearts to stamp out discrimination on their behalf. Many people with physical or sensory disabilities are quite effective at advocating for the rights of the disenfranchised in society, and there is much that we can learn from Christians with disabilities who are experienced in this arena. At the same time, many individuals with intellectual disabilities lack the power to be heard. Not only can the church be the hands and feet of Jesus on behalf of people with intellectual disabilities, but the church must be the *voice* of Jesus as well. For those individuals who do to have the ability or the power to be heard, others must respectfully step into the gap to speak boldly on their behalf. ¹⁰

It has been an unbelievable joy for our family to have been invited to participate in Joni and Friends ministries, most specifically through their annual Family Retreats offered around the country (and now around the world) each summer. We have participated in six Family Retreats thus far and look forward to our seventh this year! These retreats are essentially a summer camp experience for families and individuals with disabilities and

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¹⁰ Stephanie O. Hubach, *Same Lake Different Boat: Coming Alongside People Touched by Disability* (Phillipsburg, NJ: P & R, 2006), 200.

special needs who might otherwise not have any opportunity to experience that in the traditional way. Our first Family Retreat was in the summer of 2013, when we were still adjusting to life with Libby and Hannah. I was invited to serve as the camp pastor that week and our family was invited to participate in the retreat, along with dozens of others. It was a dual blessing to be sure as I love pouring into others as a minister of the gospel and to exercise my pastoral gift of teaching. Additionally, it was amazing to be poured into as a family with special needs children, being served, loved, and cared for with the love of Christ by some of the most self-less volunteers on the planet.

The most striking memory I have of that first Family Retreat was the scene in the cafeteria at the first dinner meal after all the families had arrived and camp had officially begun. You see, restaurants are a tricky thing for us. First, because our girls each require a wheelchair and we are a family of seven, we take up a lot of space everywhere we go, and we move a lot furniture and displace a lot of people all in the process of being seated. We are a sight to behold I assure you. Additionally, as I mentioned, our girls squeal, moan, and sometimes flail their arms excitedly and unexpectedly. They drool a lot and are regularly throwing chew toys, bibs, or pacifiers on the floor. We are not necessarily a casual or quiet crew when we go places. So, for that reason, I am used to people naturally and most often inquisitively staring at us in public. But not at Family Retreat. Not in the cafeteria at camp. In fact, I was so struck by the anomaly that everyone was just enjoying their dinner and talking and laughing and that a lot of other families were making their own noises and movements, and no one stared. I leaned over with tears in my eyes and told Mary, "We are normal here. This is the first place I feel normal."

The highlight of Family Retreat for me each year is the talent show, held on the last night of camp. Anyone and everyone is invited to participate and share their talent with the entire group. Some are very gifted, and others are very passionate, but the entertainment is pure joy and it is without a doubt one of my happiest places on earth. In our first year, a man about forty-five years old with Down Syndrome sang, "I Can Only Imagine," for which he received a standing ovation. I was sobbing and cheering, and it was incredible to hear our new friend pour out his heart in this song, which tells of a future vision of heaven with God. When he finished that song, God spoke to me. Between our family feeling "normal" at dinner and the talent show song of "imagination" that night, God reminded me that this is a snapshot of heaven on earth. Heaven will be a place of perfection; everyone loved and accepted, worshipping Jesus who made it all possible to do so. At places like Family Retreat, where for a few days everyone is accepted and loved regardless of their ability or disability, their talent or their passion, we saw a glimpse of the glory of the gospel that our future in Christ will hold. Randy Alcorn summarizes this glory:

For the Christian, death is not the end of adventure but a doorway to a world where dreams and adventures forever expand. No matter how bad the present, an eternity with Christ in Heaven will be incomparably better. So if *God* thinks the whole thing is worth it—and we know it will be worth it to *us* once we reach Heaven—then why not affirm by faith, even in the midst of suffering, that it's worth it now?¹¹

In the same way that God loves His people unconditionally, believers get a dimly lit picture of what that love looks like between one another. It is not identical of course, but it paints a glorious picture that I cling to while living this life here and now.

Challenged

I grew up playing sports. I love sports. In high school I played basketball, football, and baseball, but basketball was by far my favorite and what drew the majority of my attention and concentration. Some of my favorite memories in high school revolve around my basketball team. It was a great group of guys. We were all friends and that made practices more tolerable, road trips more fun, and games more meaningful.

I can still remember our pre-game routines. Once we had gotten taped up and dressed in our uniforms, our coach would give us a brief pep-talk in the locker room and

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¹¹ Alcorn, If God Is Good, 202.

then we would line up in the back hallway that led into our gym. One highlight that stands out revolves around that celebrated moment of entry into the gym. At our school, every season the senior class of the basketball team was allowed to create the warm-up music. This was a big choice and a great deal of planning and debate went into the selection of every song chosen. This playlist would be played during the pre-game lay-up drills as a way to fire up both the team and the crowd. We would wait for that familiar music to fire up and then excitedly make our way onto the court where the fans would begin cheering and we would hype ourselves up for the challenge ahead. We were pumping ourselves up for the challenge.

Sometimes, I feel like life with our girls requires a pre-game routine over and over again. Mary and I are continually seeking the Lord in prayer and in His Word, getting honest (and vulnerable) with one another, and leaning upon our community of faith in an attempt to get hyped up for the challenges consistently before us. I can hear the pre-game music from high school in my head even now as I write, and Guns-n-Roses has never sounded so good. But in all honesty, the challenges of suffering are real. They cannot be ignored. They are tough to digest and they are impossible to dismiss.

Some challenges are daily, like managing doctors' appointments, prescription refills, and the detailed administration of medicine, meals, and deeply personal care that our girls require. Much of this is managed and shouldered by Mary, and although she would not tell you how hard it is or complain about the toll it takes, I do not mind saying that it is a full-time job just to keep track of the insurance, therapies, doctors' orders, and government agency requirements that provide our girls the care they so desperately need. It is a challenge.

Other challenges are seasonal, like finding qualified caregivers who can help us take care of Libby and Hannah while we attempt to juggle the schedule, school, games and activities of three other very busy children and the demands of a fast-growing church. Libby and Hannah are troopers, but it is not feasible for us or best for them to try and

force them to make every event on our family calendar. That is a challenge and at times when it feels burdensome and somewhat overwhelming to navigate—I need the warm-up music of Christ to comfort and hype me up for the need before us.

My greatest challenge (or fear) however is perpetual. While I am confident and certain that our trust remains fully and completely in the Lord as it relates to the long-term prognosis for our daughters, doctors continue to tell us that their life expectancy is limited. Gratefully, no one attempts to put a timetable on anything anymore, but we are not ignorant to the reality that the girls' diagnosis brings. I cannot sugarcoat this. As their dad, this fear (challenge) has at times consumed me. I am grateful that today it does not control me, but I would also be lying if I said that it has been totally overcome.

In part, I am writing this thesis in hopes that many will see that I do not simply believe because Christ has victoriously overcome sin, death, hell, and the grave, that our lives will therefore be spared any suffering and the subsequent challenges that accompany it. No, suffering is real. The challenge is still before us. Jesus is still good, God is still sovereign, and Christ has definitively overcome. The reality of our suffering and God's sovereignty are not at odds with one another. On this fallen side of eternity, these two things will be a tension believers manage and not a problem that can be solved. God is good, and yes, his children still suffer. It is challenging, but it is true. This truth is the very center of the Christian faith, as author Tim Keller reminds, "Suffering is at the very heart of the Christian faith. It is not only the way Christ became like and redeemed us, but it is one of the main ways we become like him and experience his redemption. And that means that our suffering, despite its painfulness, is also filled with purpose and usefulness." 12

I have discovered in our story and having been "counted worthy," that our challenge serves as our confession. I do not know what is ahead for our family. I do not

¹² Timothy Keller, *Walking with God through Pain and Suffering* (New York: Penguin Random House, 2013), 163-64.

know how long God will allow my daughters (or anyone else) to live on earth. I do not know what the next trauma is going to be. I do not know if the seizures will ever stop. I do not know if we will be back in the hospital this year. I do not know what risk new viruses pose and the right precautions to take. I do not know if the girls' insurance benefits will ever be maxed out and leave us in a financial crisis. I do not know if there will be a day where Mary and I can no longer safely care for them at home. I do not know the answers to these challenges.

I confess however, what I do know. I know God is good. I know that Jesus is enough. I know that the Bible is true and has proven its reliability in my life over and over again. I know that Mary is exactly who I am supposed to be married to today and exactly who has been entrusted as the mother to my kids, because she is. I know God is in control of all things. I know the church of the Lord Jesus Christ is the greatest gift for ministering hope to the broken people and circumstances of this world. I know that God is working in the midst of all suffering, ours included. I know that on this day, there will be a that day, and on that day, God will redeem and renew and restore all that sin and Satan have stolen and destroyed.

I am trying my best to maintain my joy and trust in Jesus for this day. I appreciate the scriptural challenge Randy Alcorn gives when he writes,

Scripture commands us to rejoice in suffering because of the perseverance it produces in us. Like James (in 1:2-3), Paul said, "We also rejoice in our sufferings, because we know that suffering produces perseverance" (Romans 5:3). Paul and James both claim that we should rejoice in suffering because of what it produces: *perseverance*.

Adversity itself does not cause our joy. Rather, our joy comes in the expectation of adversity's by-product, the development of godly character. God does not ask us to cheer because we lose our job, or a loved one contracts cancer, or a child has an incurable birth defect. He tells us to rejoice because he will produce in us something money can't buy and ease will never produce—the precious quality of Christ-exalting perseverance.¹³

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¹³ Randy Alcorn, *If God Is Good: Faith in the Midst of Suffering and Evil* (Colorado Springs: Multnomah, 2009), 426.

I have heard it said before that people should not trade what they do not know for what they do know. I know there are great challenges in our life and in our family. I know there will be more. I know that suffering for believers and the sovereignty of God are both very real and true.

I know that you, the reader, will too have challenges, and I want to challenge you as you meet them. If you can embrace joy and develop a "counted worthy" mindset, then your challenges will become your confession as well. God is writing a story in the midst of your suffering. Perhaps you, the reader and fellow sufferer, need this chapter of this thesis to hype you up like a pre-game lay-up line as you prepare for whatever it is you are facing next. There are a lot of things you do not know, that is for sure. There are also a lot of things you do know, that is also for sure. Guard your heart from trading what you do not for what you do.

So, if you will indulge me, I would like to be the DJ for your lay-up line. And the playlist I have put together comes directly from the Word of God. Yes, you are facing a challenge, but a hope in God is how you are going to face whatever that happens to be. Romans 15:13 says, "May the God of hope fill you with all joy and peace in believing, so that by the power of the Holy Spirit you may abound in hope." The apostle Paul talks about a couple of things. The first is the power of the Holy Spirit at work in the lives of God's children. The second is that the evidence of this power and the passionate plea for this desire is that it (hope) would abound in our (the redeemed) lives, as God's children. The word *abound* used in conjunction with hope carries with it the idea of *hope overflowing*. By the power of God's Spirit, Paul is asking God to provide an absolutely embarrassing plethora of hope. Unshakable hope. And so, when thinking about how this works practically in our lives, as followers of Jesus Christ and members of the household of Christian faith, we must understand that our hope is sourced in God. And as hope relates to suffering, God *redeems* it. In the book *Why, O God?* the authors beautifully summarizes this truth:

God redeems suffering. The God of life is the only one who can conquer death by embracing it. And so death no longer has the victory, and neither does suffering. Christ has given it meaning, not only for salvation but also for sanctification, and that is the best part. It tells us we are no longer alone in our hardships, our disabilities. Our suffering is not a flip of the coin; it is not a fluke of fate. We are not in the middle of some divine cosmic accident. No, our suffering can be *redeemed*. Oh, the wonder of such a thought that it is all for our sanctification, our relationship with him, and our witness to a world in need of redemption. ¹⁴

This truth about God's redemption of humanity's suffering is how the redeemed people of God prepare for every game every day and face each challenge, however difficult they may be. Our hope finds its substance in Jesus, and our hope is supplied by the Holy Spirit, which is how we can be confident while we long for something greater in our future. So here is hoping that you, a fellow sufferer, always remember these verses.

Philippians 1:6

Philippians 1:6 says, "He who began a good work in you will bring it to completion at the day of Christ Jesus." Scholar Gordon D. Fee gives encouraging explanation in his commentary on Philippians, when he writes.

Paul is still not done with his thanksgiving. His mention of their participation in the gospel *from the first day until now* leads him to add, in a somewhat digressive way, that he is fully *confident* that what was true *from the first day* and is still true *now* will be true at the end as well. But this confidence has very little to do with them and everything to do with God, who both *began a good work*, which is still in evidence, and will *carry it on to completion until the day of Christ.* 15

Be comforted, fellow sufferer, God will finish the good work in you that he has begun.

Deuteronomy 31:6

Deuteronomy 31:6 reads, "He will never leave you or forsake you." As has been said throughout this body of work, God will never abandon those who know and love him. Allow that truth to bring encouragement as you endure.

¹⁴ Larry J. Waters and Roy B. Zuck, *Why, O God? Suffering and Disability in the Bible and the Church* (Wheaton, IL: Crossway, 2011), 17-18, emphasis original.

¹⁵ Gordon D. Fee, *Philippians*, The IVP New Testament Commentary Series, vol. 11 (Westmont, IL: IVP, 1999), 47-48.

First John 1:9

First John 1:9 says, "If we confess our sins He is faithful and just to forgive us and to cleanse us of all unrighteousness." Our responsibility as Christ-followers is confession, but God does the miraculous work of forgiveness and cleansing. Redemption belongs to Jesus, and repentance is the part for Christian sufferers to embrace. ¹⁶ I appreciate the commentary offered by Howard Marshall regarding the forgiveness of God and its condition being based entirely upon the beauty of God's character.

To confess sins is not merely to admit that we are sinners, but to lay them before God and to seek forgiveness. If we do so, we can be sure of forgiveness and purification on the grounds of God's character. He is just and faithful to forgive confessed sin. The faithfulness lies in his adherence to his promises that he will forgive his people: "Who is a God like thee, pardoning iniquity and passing over transgression for the remnant of his inheritance? He does not retain his anger forever because he delights in steadfast love.¹⁷

This is the miracle of grace that is worthy of thought and the source of joy, for those who know and are loved by God.¹⁸ Hold tightly to it fellow sufferer. Do not grow discouraged. God is in control and his love is evident all around.

Romans 10:10

Romans 10:10 reads, "If we confess with our mouths that Jesus is Lord and believe in our hearts that God raised him from the grave, we will be saved." My fellow sufferer, salvation from sin and the eternal rescue from God is only as far away as one's asking. ¹⁹ Trust in God to forgive sin and believe that he alone has the capacity to

¹⁶ Stephen S. Smalley, *1, 2, 3 John*, Word Biblical Commentary, vol. 51 (Dallas: Word, 1984), 32.

¹⁷ I. Howard Marshall, *The Epistles of John*, The New International Commentary on the New Testament (Grand Rapids: Wm. B. Eerdmans, 1978), 113-14.

¹⁸ Robert W. Yarbrough, *1-3 John*, Baker Exegetical Commentary on the New Testament (Grand Rapids: Baker, 2008), 64.

¹⁹ Thomas R. Schreiner, *Romans*, Baker Exegetical Commentary on the New Testament, vol. 6 (Grand Rapids: Baker, 1998), 465.

complete the work. The promise is that upon the confession of faith in Christ, salvation is immediate and forever.²⁰ There is *nothing* that could be greater than that.

Romans 8:38-39

Romans 8:38-39 says, "For I am sure that neither death nor life, nor angels nor rulers, nor things present nor things to come, nor powers, nor height nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord." The reality of knowing with all confidence that no suffering can separate those who are in Christ from his enduring love is nothing but grace and mercy made known. I find encouragement in the commentary offered by author C. E. B Cranfield as it relates to the tremendous confidence believers in Christ can have and hold in the most difficult seasons of suffering. The author helps to explain Paul's positivity and pre-game speech worthy encouragement, when he writes,

What Paul is here concerned to say is simply that there is no spiritual cosmic power, whether benevolent or malevolent, which will be able to separate us from God's love in Christ. And this he can say with confidence, because he knows that Christ has once and for all won the decisive battle against the rebellious powers (cf. Col. 2:15: also Eph. 1:21, 22a; 1 Peter 3:22), so that their effectiveness has been drastically curtailed and their final complete subjection assured.²¹

Psalms 42:5-6

Psalms 42:5-6 reads, "Why are you cast down, O my soul, and why are you in turmoil within me? Hope in God; for I shall again praise him, my salvation and my God." Christians can rest in the truth that they have been counted worthy by the God of the universe to steward this season of suffering for as long as God has determined it will be. That challenge is also their confession. It is their opportunity to tell of what they believe,

²⁰ Douglas J. Moo, *The Epistle to the Romans*, The New International Commentary on the New Testament (Grand Rapids: Wm. B. Eerdmans, 1996), 545.

²¹ C. E. B. Cranfield, *A Critical and Exegetical Commentary on the Epistle to the Romans,* International Critical Commentary (London: T & T Clark, 2000), 442.

to whom they belong and where their trust is found. It is not easy, but it is possible with God. Anything is possible with God. Christians can do this. They are not alone.

God is with you, fellow sufferer. The church of the Lord Jesus Christ can be a gift to you. God has men and women who will walk beside you. God sees you. God hears you. He has not forgotten you. If you are in Christ, you are going to win. You have got this. God loves you. Always, forever, he loves you.

CHAPTER 5

CONCLUSIONS ABOUT SUFFERING FOR THE BROADER CHURCH

This chapter will serve to conclude the conversation about the theology of suffering as experienced through our family's personal story. The chapter will offer five critical elements learned through the study of God's Word and applied through the tragedy of personal suffering. This chapter aims to serve the church at large in equipping her for the difficulty of ministry in the mire of suffering.

God's Sovereignty over Suffering

One thing that is clear from the Scriptures is that God is completely in control of all things at all times. It could be argued that God is not ultimate if he is not ultimately sovereign. The Bible gives ample evidence as to the sovereignty of God and his control over all things at all times. Psalm 103:19 says, "The LORD has established his throne in the heavens, and his kingdom rules over all." Jeremiah 32:17 reads, "Ah, Lord GOD! It is you who have made the heavens and the earth by your great power and by your outstretched arm! Nothing is too hard for you." Romans 11:33-36 tells, "Oh, the depth of the riches and wisdom and knowledge of God! How unsearchable are his judgments and how inscrutable his ways! For who has known the mind of the Lord, or who has been his counselor? Or who has given a gift to him that he might be repaid? For from him and through him and to him are all things. To him be glory forever. Amen." Colossians 1:16-17 says, "For by him all things were created, in heaven and on earth, visible and invisible, whether thrones or dominions or rulers or authorities—all things were created through him and for him. And he is before all things, and in him all things hold together."

Revelation 21:6a reads, "And he said to me, "It is done! I am the Alpha and the Omega, the beginning and the end."

For the sufferer, it is critically important to embrace the sovereignty of God at all times. If God were not sovereign, then the hope of those who suffer would be left to whatever the best their circumstances are able to provide. In a fallen and broken world, the only hope for navigation with sincerity of faith, purity of heart, and genuine hope is the complete and awesome sovereignty of God. One Scripture stands out as a great example of God's people finding ultimate hope in God's sovereign rule, in the midst of their terrible personal suffering.

In Exodus 2, the Bible records a turning point for the Jewish people who had endured more than four hundred years of slavery under the heavy and oppressive hand of Egyptian Pharaohs. Verses 23-25 say, "During those many days the king of Egypt died, and the people of Israel groaned because of their slavery and cried out for help. Their cry for rescue from slavery came up to God. And God heard their groaning, and God remembered his covenant with Abraham, with Isaac, and with Jacob. God saw the people of Israel—and God knew." Four different evidences of God's sovereign rule and control are listed in these few verses of Scripture. Each one should provide the Christian sufferer with comfort as they endure their own season of suffering and hardship.

First, in verse 24, the Bible says that God *heard* the people's groaning. What an incredible reality to know that God hears his people. Not only does God hear, but the Scripture is clear that what God heard was groaning. It was pain that God was listening to. It was cries for help. The Bible says God heard the screams of those are battling the most tragic circumstances and deepest forms of personal suffering. There can be a temptation to see God, perhaps even because of his sovereign status, as a holy being who is not bothered with the cries, pain, and sounds of his suffering subjects. However, that assumption would not be true. God hears. Christians should find hope in the fact that the

sovereign God of the universe hears his people when their suffering makes them cry out for help. He is listening.

Second, not only does God hear the cries of help that his people offer up, but the Bible says further in verse 24 that God *remembered* his covenant with Abraham, with Isaac, and with Jacob. Simply stated, God remembered his promise from Genesis 12 that he would build a nation for himself and that he would bless them, keep them, and use them to bring himself glory and the suffering world good. Therefore, in the same way Christians find comfort knowing that God hears their cries, one can likewise find solace knowing that the God of the universe, the sovereign ruler of all things at all times, remembers his promises. And God has promised his redeemed that suffering does not have the final word. God has promised that suffering will one day end. God has promised that those who belong to him will be ultimately and finally rescued from the snare of suffering and therefore can live in its midst with a transcendent hope. One should think about the words, the promise, of Jesus to his disciples just before his ascension into heaven: "And behold, I am with you always, to the end of the age" (Matt 28:20b). Fellow sufferers should cling to the promise of God that he is with his children always, in every moment of suffering, and he remembers his promises, always.

Third, in verse 25, Scripture tells that God *saw* the people of Israel. What an incredible thought it is, to know that the sovereign God of the universe who is holding the entire creation together, sees all things at all times. What is more incredible is that the Scriptures are specific to include his seeing his people in the midst of their suffering. God sees suffering. He is always aware of it. His sovereignty demands his knowledge of it; his knowledge of it can be attributed to his seeing it. The writer of Job tells of God seeing all things at all times in hopes of encouraging faith and obedience, given the natural human tendency toward worry and fear instead: "God understands the way to it, and he knows its place. For he looks to the ends of the earth and sees everything under the heavens" (28:23-24) Likewise, the writer of Hebrews speaks to the sovereign seeing of God when he

writes, "And no creature is hidden from his sight, but all are naked and exposed to the eyes of him to whom we must give account" (4:13). Therefore, the Christian who is embattled in suffering can be comforted as the sovereignty of God can be understood by his seeing all things, most especially seeing his people who are mired in the suffering itself.

Finally, at the end of Exodus 2:25, the final three words are, "and God knew." God *knew* exactly what, why, how, and where his people were suffering, which gives the final bit of clarity as to the sovereignty of God, which can be gleaned from this particular text of Scripture. D. A. Carson adds some clarity about the sovereign knowledge of God as a comfort to the faithful follower of Christ: "In reality, we never escape God's sovereignty. Part of learning to live as faithful children of the sovereign God is therefore tied to trusting him when he can at best be only dimly discerned behind events and circumstances that the Bible itself is quick to label evil." Sufferers can be comforted with the clear biblical truth that God knows what is being endured, why it is being endured, how it is being endured, and where it is being endured. He always knows; his sovereignty demands it.

The sovereignty of God is an incredible reality for the Christian to rest in. God is in control of all things at all times. That fact, his sovereign control, is what makes him God. His sovereign control is revealed in his hearing the cries of those who belong to him, as he heard Israel's cries suffering slavery. His sovereign control is revealed in his remembering his promises, as he remembered his covenant with Abraham, Isaac, and Jacob. His sovereign control is revealed in his seeing all things at all times, including the suffering of his people. God's sovereign control is revealed in his knowing. God knows everything, including what his people need and what their suffering is producing in and through them.

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¹ D. A. Carson, *How Long, O Lord? Reflections on Suffering and Evil*, 2nd ed. (Grand Rapids: Baker, 2006), 67.

God's Presence in Suffering

In addition to God's sovereign rule over all things at all times, fellow sufferers can find eternal comfort in the powerful presence of God, being with sufferers in the middle of their suffering. Admittedly, this idea of God's presence is difficult for many to grasp, as the natural tendency for most people is to withdraw and feel isolated in the difficulty that suffering often brings. But, God is an unchanging constant and the Bible tells that he remains with those who belong to him, in every moment of every day.² That would include the best times that demand celebration, and the worst times that yield grief and sorrow as well. God's presence is made available to Christ-followers by God giving his very Spirit.

Jesus spoke about the presence of God as a promise for the Christian when he said, "If you love me, you will keep my commandments. And I will ask the Father, and he will give you another Helper, to be with you forever, even the Spirit of truth, whom the world cannot receive, because it neither sees him nor knows him. You know him, for he dwells with you and will be in you" (John 14:15-17). This passage is part of a larger discourse that stretches from chapters 13–16 of John's gospel, and at the center of this discourse Jesus is teaching on the Holy Spirit. He is promising His disciples that the very presence of God is going to dwell inside of them, empowering them with a supernatural power to accomplish the mission of God. This would include God's very presence in every Christian's personal suffering. Therefore, sufferers should embrace the Holy Spirit as Helper, given as God's presence living within the Christian.

In the ESV translation, the word given to describe the Holy Spirit is "Helper." And that word "Helper" is the Greek word *Paraclete*. It can also be translated "counselor" or "advocate." It implies the idea of one who comes along side to aid another. In other words, the Holy Spirit is one who is called to continually stand by a person's side. He is ever ready to stand by the suffering Christ-follower and participate in

² "Jesus Christ is the same yesterday and today and forever" (Heb 13:8).

everything in which His help is needed. Sometimes when one thinks of the Holy Spirit, he seems to be so far away and distant, but when the Christian thinks of the "Paraclete," literally the "helper," "counselor," "comforter," "advocate," or "standby," it gives the right idea.

It is worth noting that Jesus is talking to His disciples about His departure and they are naturally a little worried and fearful of what is to come. Jesus has been their "helper," but Jesus uses the word "another" to describe "the Helper" who is coming. "Another" is the Greek word *allos*, which means "another of the same kind," as opposed to the Greek word *heteros*, which means "another of a different kind." In other words, Jesus is saying, "the Help that I am sending to you is just like me." This is why there are times in the Scripture when the Holy Spirit is referred to as the Spirit of Christ. For example, the apostle Paul says, "Those who are in the flesh cannot please God. You, however, are not in the flesh but in the Spirit, if in fact the Spirit of God dwells in you. Anyone who does not have the Spirit of Christ does not belong to him" (Rom 8:8-9) The apostle Peter likewise says, "Concerning this salvation, the prophets who prophesied about the grace that was to be yours searched and inquired carefully, inquiring what person or time the Spirit of Christ in them was indicating when he predicted the sufferings of Christ and the subsequent glories" (1 Pet 1:10-11)

Just as Jesus came alongside the twelve disciples as their "helper," the Holy Spirit now dwells inside of every disciple and serves as "Helper." Specifically, Jesus says in verse 17, "He will be in you." This is a miracle! The suffering follower of Jesus is never alone. The suffering follower of Christ is never without the power to accomplish what God has called him to. No sufferer is lacking the strength to endure because each has the Helper, who walks with him, empowers him, and strengthens him if he trusts and rests in him. In addition, Jesus says in verse 16 that the Helper is with Christ-followers "forever!" If someone is *in Christ*, then there is never a time when he is alone, never a time when he is lacking the power or strength to accomplish what God has called him to endure.

This gift leads to the second truth seen in Jesus' teaching on the Holy Spirit. In John 16:5-7 Jesus says, "But now I am going to him who sent me, and none of you asks me, 'Where are you going?' But because I have said these things to you, sorrow has filled your heart. Nevertheless, I tell you the truth: it is to your advantage that I go away, for if I do not go away, the Helper will not come to you. But if I go, I will send him to you." The disciples are literally paralyzed with fear and sorrow because Jesus has told them He is leaving. They must have been thinking, "What do you mean you are leaving?" But one should listen to the astonishing response Jesus gives: "Nevertheless, I tell you the truth: it is to your advantage that I go away, for if I do not go away, the Helper will not come to you. But if I go, I will send him to you" (John 16:7). Jesus just said that it is to their advantage that he go away. Pastor Dane Ortlund describes the comfort for Christians, via the presence of God:

Our tendency is to feel intuitively that the more difficult life gets, the more alone we are. As we sink further into pain, we sink further into felt isolation. The Bible corrects us. Our pain never outstrips what he himself shares in. We are never alone. That sorrow that feels so isolating, so unique, was endured by him in the past and is now shouldered by him in the present.³

The presence of God is one of his greatest gifts to sufferers. To know with all confidence that God is near and never leaves brings a supernatural peace and hope that allows the suffering itself to be endured.

Suffering Christians can find comfort in the presence of God as he gives his Holy Spirit because Jesus declares the Holy Spirit is for their *advantage*. Jesus makes such a bold statement because the Holy Spirit dwells "in us." Remembering 14:17, Jesus, speaking of the Holy Spirit, said, "You know him, for he dwells with you and will be in you." This is a huge internal reality of God's presence. Jesus' human presence came with physical limitations while on earth. He was not physically present at all places at all times. He was not *always* with His disciples. But now that Christ-followers and fellow sufferers

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³ Dane Ortlund, *Gentle and Lowly: The Heart of Christ for Sinners and Sufferers* (Wheaton, IL: Crossway, 2020) 44.

have been given the indwelling Spirit, they are *never* alone. God's presence is always, supernaturally with us. God's presence is with Christians in all moments, all the time, meaning that those suffering are never suffering alone.

God's Goodness Despite Suffering

Christianity is unique in its approach to suffering. Not only is God in control of the good things that happen, but He is in control of the bad things that happen as well. This is a testimony to his sovereign control, as spoken of earlier in this chapter. Therefore, the bad things that happen in people's lives are never without divine purpose. While people, as finite beings, they do not always understand why God allows specific suffering to happen to specific people at specific times, it is important to know that that suffering is never wasted with God. As author Elizabeth Elliot has titled her book, *Suffering Is Never for Nothing*.

Throughout this thesis, the story from John 9 has been dissected and studied in detail. As has been noted, Jesus' disciples, like most Jews of their day, linked sin and suffering together. Of course, as has been observed, in one sense they are correct: the introduction of sin, as seen in Genesis 3, caused suffering, pain, and death to enter creation as a whole. Also, while those things are consequences of sin in the broadest sense, they fail to pinpoint the reason bad things happen to good people. In fact, the Old Testament book of Job is one of the definitive examples of why this kind of thinking is not the way biblically faithful believers should approach the subject of suffering. That said, however, most can relate to the disciples' line of questioning in regard to the issue of suffering. They are essentially asking Jesus, "What went wrong that explains this man's blindness?"

Picking up on what the disciples are asking, Jesus demolishes the commonly shared theology of his day that suffering is nothing more than a cause-and-effect relationship. He points out that the blind man was not blind because of anyone's specific sin; rather, the man's suffering exists that the works of God would be displayed in-and-through his life. God sovereignly controls the details of every life for His bigger,

redemptive, purpose. Jesus never said the man's suffering would be easy for him to bear or that it would be something anyone would fully understand in the midst of enduring or observing it. Jesus only says that His suffering will *not* be without divine purpose. The Christian knows that a life fully surrendered to Jesus does not prevent someone from facing suffering. It does, however, empower all Christ-followers to endure whatever suffering they may face by God's grace, for His glory, and for their own good. Christians who suffer should realize that because their suffering costs so much, the suffering itself is far too precious to waste. There are a few ways the suffering Christ-follower can reconcile the goodness of God in the midst of the suffering of man.

First, suffering can exist for the glory of God. As one suffers, he must think deeply about Jesus' suffering so he does not waste his suffering. God repurposes suffering and will use all of it for His glory and the advancement of His kingdom. In Jesus, God did not suffer so that Christians would not suffer. He suffered so that when Christians do suffer, they can become more like Him and point more people to Him. Becoming like Jesus in suffering requires reflecting on Jesus' life, own suffering, and vindication. The primary purpose of His suffering was to glorify God the Father by perfectly revealing true justice, mercy, and faithfulness at once. Afterwards, Jesus was resurrected by God the Father through God the Holy Spirit, and Christians eagerly await the day he will come back to right every wrong and institute a new creation that is free from sin's damaging effects, including suffering.

Second, suffering can exist for the good of others. The apostle Paul is probably one of the best examples. When Paul faced suffering, he did it with seriousness of faith and peace of mind. He did not avoid it out of fear or wallow in self-pity because of it. Paul knew that, in Christ, misery can become ministry. Likewise, Christ-followers may face suffering as they preach the gospel and live as citizens of the kingdom of God. However, Jesus makes the Christian's suffering meaningful, purposeful, and valuable because he invites him to participate in God's good work to see lives changed, restored,

redeemed, and healed by the power of the gospel of Christ. The redemption of God is played out in the lives of his people, including and especially through the difficulty and hardship of suffering, and a lost world is watching while the grace unfolds.

Third, suffering can exist for personal and spiritual growth. When Christians experience affliction, they have a unique opportunity to learn a few things that help them grow as believers. First, they gain a deeper understanding of how humble and gracious God is, to first serve them as their Suffering Servant in the person of Jesus. God himself, humbly came to serve, not to be served! Second, Christ-followers learn to better love and appreciate those who serve them. Christians discover the depth of other's love for them when they are hurting, needy, and inconvenient. Those who serve them and reflect the character of Jesus most clearly in those seasons of suffering become the greatest gifts to them. Third, as they are served both by Jesus and by others, they learn new ways to serve others who suffer as well. Anyone can easily become consumed with their own lives and likewise callous to the needs of others. However, through suffering, God often teaches people to open their hearts, their eyes, their hands, and their finances, to meet the needs of others who are suffering around them.

Fourth, suffering can exist for establishing credibility. When someone is afflicted, they have a unique credibility to speak about difficult subjects in a way that helps bring healing to others facing the same afflictions. This is what the apostle Paul meant when he wrote to the Corinthian church, and said,

Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and God of all comfort, who comforts us in all our affliction, so that we may be able to comfort those who are in any affliction, with the comfort with which we ourselves are comforted by God. For as we share abundantly in Christ's sufferings, so through Christ we share abundantly in comfort too. (2 Cor 1:3-5)

In fact, through his own sufferings Jesus fully identifies and empathizes with humanity's suffering. Until Jesus returns, Christ-followers are gifted a divine appointment, through sufferings, to become more like Jesus and tell people about the God who identifies and empathizes with them.

Finally, suffering can exist for discovering deep joy. Admittedly, while this seems unusual to think about a positive connection between joy and suffering, the Scriptures are clear that both can co-exist. Author Jerry Bridges talks about this connection of joy and suffering:

Both Paul and James speak of rejoicing in our sufferings (see Romans 5:3-4; James 1:2-4). Most of us, if we are honest with ourselves, have difficulty with that idea. Endure them, perhaps, but rejoice? That often seems like an unreasonable expectation. We are not masochistic; we don't enjoy pain. But Paul and James both say that we should rejoice in our trials because of their beneficial results. It is not the adversity considered in itself that is to be the ground of our joy. Rather, it is the expectation of the results, the development of our character, that should cause us to rejoice in adversity. God does not ask us to rejoice because we have lost our job or a loved one has been stricken with cancer or a child has been born with an incurable birth defect. But he does tell us to rejoice because we believe he is in control of those circumstances and is at work through them for our ultimate good. The Christian life is intended to be one of continuous growth. We all want to grow, but we often resist the process. This is because we tend to focus on the events of adversity themselves, rather than looking with the eve of faith beyond the events to what god is doing in our lives. It was said of Jesus that he "for the joy set before him endured the cross, scorning its shame" (Hebrews 12:2). Christ's death on the cross, with its intense physical agony and infinite spiritual suffering of bearing God's wrath for our sins, was the greatest calamity to ever come upon a human being. Yet Jesus could look beyond that suffering to the joy set before him. And, as the writer of Hebrews said, we are to fix our eyes on him and follow his example. We are to look beyond our adversity to what God is doing in our lives and rejoice in the certainty that he is at work in us to cause us to grow.⁴

The goodness of God is not affected because of the bad that accompanies suffering. For the Christ-follower, it is often through the tragedy and trial of suffering that the goodness of God is seen most clearly. While suffering might still be categorized as bad, God is always understood as good, and sometimes the very subject of suffering itself allows that truth to be most evidently known.

God's Provision for Suffering

One of the greatest realities that suffering has shown to the Bales family, through our story of suffering, is the genuine gift of biblical community that is afforded

⁴ Jerry Bridges, *Trusting God: Even When Life Hurts* (Colorado Springs: Nav Press, 2016), 174-75.

the Christian, primarily through the local church. This grace of God is never more powerfully displayed than when members of the body of believing Christ-followers finds themselves in the midst of a trial or season of suffering. This is certainly the testimony of our family, both as the recipients of God's grace poured out through his people and, on occasion, as the administrators of God's grace, serving as an instrument in his hand through the ministry to someone else. This is the gospel of Christ alive and at work, actively redeeming the brokenness of a fallen world.

The gospel frees Christians to devote themselves to God through his Word, through the connection with one another, and through a prayer life as Christ himself modeled. In the New Testament letter of Acts, the author and church historian, Luke, records the power, majesty, and redemption made manifest through a Spirit-filled local body of believing Christ-followers. Luke writes, "And awe came upon every soul, and many wonders and signs were being done through the apostles" (Acts 2:43). Careful attention should be given to the word "awe." For every attentive reader, this should demand the self-examination to question, when is the last time you, the reader and fellow sufferer, were in awe of something?

It is crystal clear in this text that this New Testament church had believers, and a watching world of unbelievers as well, in awe. The world wonders at the selfless, redemptive, and God-given power of a unified people when the church meets the needs of its members, most often and honestly seen during moments of suffering. It can be said that when the church is working right, there is *nothing* on earth like it! No organization, despite its mission statement or vision or strategy for meeting needs, can compare to the church of Jesus Christ when it is meeting its redemptive potential. This would certainly include when the ministry of presence, through the power of God's people, is on full display during the seasons of suffering and difficulty of trials, which are certain to be a part of every life lived. People are in awe of God when the church is at its best. But, why? Is this because Christians are amazing? No, it is because God is! By the power of God's

Holy Spirit, when believers are devoted to God's Word, to one another, and to prayer, miracles happen and the result is awe.

Luke continues to explain how this awe showed up and the provision of God was on even greater display, when he wrote, "And all who believed were together and had all things in common. And they were selling their possessions and belongings and distributing the proceeds to all, as any had need" (Acts 2:44-45). Two more keys are worthy of attention. First, is the phrase "in common," and second is the phrase "as any had need." There is something wonderfully strange about the church: the people who are within it. Think about the incredible nature, as it relates to the diversity, of the church. Then, think about how that diversity is deployed by the Holy Spirit of God at work in this diverse make-up of Christians for the purposes of serving together and meeting the needs of one another. All of this miraculous grace, while the world watches in wonder and awe.

In 1 Corinthians 12, Paul equates the church and its members with body parts. He says that the hand is not more important than the foot, but that each is equally important, and both are needed for the body to function as God designed. The church is a body of believers made up of an incredibly unique group of individuals, yet the gospel of Jesus Christ gives a commonality that cannot be enjoyed outside of the church. Biblical community unites the people around the greatest thing they could ever share with anyone else, Jesus Christ. It does not matter background, economic status, race, gender, or personal preference; if someone is a Christian, that person has the greatest reality in common with every other Christian. That commonality is salvation by God's grace and through his given faith in the shed blood of Jesus Christ for the forgiveness of sins.

Additionally, Paul notes that the early church met the needs of its members.

What is incredible is that it was local church brethren meeting the needs of fellow brethren. Author Jerry Bridges expounds,

Trials and afflictions have a leveling effect among believers. It has often been said that "the ground is level at the foot of the cross." That is, regardless of our wealth or power or station in life, we are all alike in our need for a Savior. In the same way, we are all alike subject to adversity. It strikes the rich and the poor, the powerful and

the weak, the superior and the subordinate, all without distinction. In times of adversity we tend to set aside such notions of "vertical" relationships and relate to one another on a horizontal level as brothers and fellow sufferers. John could have rightly identified himself as an apostle of Jesus Christ, as one in a position of spiritual authority over the suffering believers in Asia. Instead he chose to identify himself as a brother and companion in their suffering. Trials and afflictions also have a mutual drawing effect among believers. They tend to break down barriers between us and dissolve any appearance of self-sufficiency we may have. We find our hearts warmed and drawn toward one another. We sometimes worship together with another person, pray together, and even serve together in the ministry without ever truly feeling a bond of fellowship. But then, in a strange way, adversity strikes us both. Immediately we sense a new bond of fellowship in Christ, the fellowship of suffering. There are many elements that go into the total concept of fellowship, as it is described in the New Testament, but the sharing together in suffering is one of the most profitable. It probably unites our hearts together in Christ more than any other aspect of fellowship.⁵

This gift of the church, meeting the needs of its own, is our family's testimony over and over again. Without failure, our own biblical community has provided meals for our family, mowed our yard, kept our kids, or bought groceries at times when our girls have been in the hospital sick. This is the provision of God through the gift of his church. When God's church is reaching its redemptive potential, there is nothing else on earth quite like it.

God's Promise to End Suffering

The Christian lives each day with an understanding that, through Christ, some of what God has promised according to his Word has been fulfilled, and some is still to come. Theologians have referred to this era of tension as the phenomena of "already and not yet." While suffering, as a consequence of sin's introduction into God's holy and perfect creation, is a reality for now, there is a day coming when it will be no more. However, today, suffering's end is not yet. In light of this clear and explicit biblical truth, the suffering Christian must live each day, most especially those plagued with trial and hardship, with an expectant hope. There must be a longing for the day when Christ ends

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⁵ Bridges, *Trusting God*, 190-91.

all that is wrong with creation and sends sin, suffering, and death to its final destination: hell.

D. A. Carson expounds upon the reality of a coming day when suffering will end:

This tension between the "already" and the "not yet"—the kingdom has already arrived, and the kingdom has not yet come—is a commonplace of biblical thought. It has many important connections with other elements of Christian truth, but the one that interests us here is its bearing on evil and suffering. To put the matter in a nutshell: once the consummated kingdom has dawned, there will be no more evil or suffering among the Lord's people. But meanwhile, even though the kingdom of God has been inaugurated, evil and suffering are on the one hand said to be defeated in principle, and yet on the other are palpably present and in some ways can be expected to increase.⁶

This future hope is good news for the Christian. This is the declaration of Jesus himself in John's gospel: "I have said these things to you, that in me you may have peace. In the world you will have tribulation. But take heart; I have overcome the world" (John 16:33). For the suffering Christian, hope is rooted deeply within this declaration of Christ that he has overcome. Suffering will not have the final say, because Christ has spoken. In a similar way, the apostle John reflected upon this era of tension when he received and recorded his revelation from God: "Do not fear what you are about to suffer. Behold, the devil is about to throw some of you into prison, that you may be tested, and for ten days you will have tribulation. Be faithful unto death, and I will give you the crown of life" (Rev 2:10). The apostle wrote these words to Christians. He offered this encouragement to the persecuted followers of Christ living in Smyrna, and his hope was to endure because the end is worth it. Suffering is limited by time and God sets the clock. In fact, the writer explains that the crown of life is a reward of royalty, which is reserved for those who endure persecution, trial, suffering, to the end.

The hope of heaven gives the Christian, even in the midst of suffering, a graceempowered perspective that places focus and attention on the end, while enduring the

⁶ Carson, How Long, O Lord?, 122.

hardship of the here and the now. Carson offers a convictional explanation of the need to view the hope of heaven while battling the daily challenges in the present:

Christians ought to be developing a kind of homesickness for heaven. Some want to warn us against being so heavenly minded that we will be no earthly good. I suppose that is possible, but I haven't found anyone like that yet. Puffed up piety and sentimental religion can make one think much of heaven and love no one down here, but those who are genuinely heavenly minded have the highest incentive to serve well here: they are laying up treasure in heaven. Preaching and teaching that do not constantly make heaven the Christian's hope and goal are not only unfaithful to the Scriptures, but rob believers of one of the most important perspectives for helping them to cope with pressures here and now. The drift in much popular American evangelicalism at the moment is toward evangelical pop psychology: sanctify the terminology and apply the benefits of pop theories on self-understanding. I would not say these developments are entirely without value. But if they displace a robust Christian faith that deals with guilt, suffering, values, faith, fidelity, hope, mercy, truth, righteousness, justice, forgiveness, and much more on biblical grounds, we have squandered our birthright for a mess of pottage.⁷

The promise of God to end suffering and redeem those who have endured it, is central to the Christian faith. This hope of heaven, which is reserved for the suffering believer in Jesus Christ, remains an encouragement to our family and something in which I consistently share with fellow sufferers in moments of ministry when hope for endurance is desperately needed and obviously absent.

Ultimately, when John receives the vision of God's new heaven and his new earth, he describes a picture that sufferers can cling to and count upon as the future reality, even in these not yet days of right now:

Then I saw a new heaven and a new earth, for the first heaven and the first earth had passed away, and the sea was no more. And I saw the holy city, new Jerusalem, coming down out of heaven from God, prepared as a bride adorned for her husband. And I heard a loud voice from the throne saying, "Behold, the dwelling place of God is with man. He will dwell with them, and they will be his people, and God himself will be with them as their God. He will wipe away every tear from their eyes, and death shall be no more, neither shall there be mourning, nor crying, nor pain anymore, for the former things have passed away. (Rev 21:1-4)

I personally find great comfort during the hardest days our family endures in this picture of sin gone, suffering laid to waste, and all life's tragedies and hardships gone forever.

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⁷ Carson, How Long, O Lord?, 130-31.

I am able to take great comfort, as a Christ-follower and someone well versed in personal suffering, knowing that Christ makes ultimate and perfect provision to end all suffering. The language of the Bible offers a hope that no doctor or test can provide with any chance to compete. It is a joy to continue to grow in my own discovery regarding my abiding, biblical theology of suffering. God is faithful to stretch me, mold me, and shape me. In his infinite wisdom and abounding grace, he has chosen to use the most wonderful tools ever imagined, two little girls named Libby and Hannah. Suffering is not easy, but suffering is never wasted. God has counted us worthy to suffer. We suffer for his glory and we suffer for our good.

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ABSTRACT

COUNTED WORTHY: A FATHER'S PERSPECTIVE ON THE THEOLOGY OF SUFFERING

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This work seeks to offer a deeply empathetic and unique resource on suffering that can help navigate necessary theology for sufferers when faced with trial and tragedy. Clear biblical teaching regarding the sovereignty of God in and over suffering will be shared, while highlighting personal examples as the proving ground for this truth. This work aims to help equip the Church with a more robust theology of suffering, but as given from the raw perspective of a fellow sufferer. I want to lovingly and honestly challenge sufferers to assess their own conviction regarding how their personal suffering has affected their awareness of the presence of God and their disposition toward him. This work is ultimately given as an encouragement and source of strength for sufferers, who might find the authenticity of my family's story a validation of the convictions shared, as founded upon the truth of God's eternal word.

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