

MARRIAGEABILITY

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*Embracing the Richness of a Marriage
Affected by Disability*



JOAN M. BORTON

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MarriageAbility

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*To my Junior Shepherd, Jerry Lee Borton,
who loves me and cares for me
while heartily following the Senior Shepherd,
our Lord Jesus Christ*

CONTENTS

Foreword 1

Introduction 5

SECTION ONE ELEMENTS OF A BIBLICAL MARRIAGE

Chapter One: *Becoming One* 11

Chapter Two: *Submit or Die* 19

Chapter Three: *Vows and Dreams* 31

Chapter Four: *Intimacy* 45

SECTION TWO THE DAILINESS OF DISABILITY

Chapter Five: *Adjustments* 59

Chapter Six: *Typical Spouse Roles* 71

Chapter Seven: *The Caregiving Spouse* 79

Chapter Eight: *Home and Family* 91

Chapter Nine: *Attendant Care* 103

Chapter Ten: *Travel* 115

Chapter Eleven: *Make Room for Fun* 129

Chapter Twelve: *Aging* 143

SECTION THREE LIFE IN COMMUNITY

Chapter Thirteen: *Hard Truths* 157

Chapter Fourteen: *Is Marriage for Me?* 167

Appendix 185

Cincinnati Chili Recipe 185

Buckeye Recipe 186

Resources 189

Acknowledgments 191

Endnotes 195

FOREWORD

I'm glad you picked up this book. My prayer is that it both encourages and challenges you.

I can assure you that the author knows a few things about marriage and disability. I've been her husband for almost twenty-eight years. Over the years God continues to mold us into his image and make us one.

Along with the joys and challenges of marriage, we live with the everyday realities of my disability. I was born with cerebral palsy (CP) and use a power wheelchair. Every person with cerebral palsy is different. For me, it means that the part of my brain that controls my balance and coordination is damaged. This means that the messages don't get through correctly from my brain to the rest of my body. I know this is an oversimplified definition, but this is a book on marriage and disability, not a science textbook.

Joan and I got married in our mid-thirties. At the time, each of us was coming to terms with the idea that we might never marry. For me, dating was difficult. Sometimes years went

by between dates. I would try too hard. I expected too much. I poured all my energy into ministry.

I'd met Joan seven years earlier at a disability ministry conference in Wisconsin. There were forty-eight people there. She remembers me because she said I was funny and wore polyester. In my defense, polyester is easier for transfers. I don't remember meeting her. I'm pretty sure she has forgiven me by now. Thank you, Jesus, . . . and Joan.

We met again the next year at a conference in Michigan. There were over nine hundred people there. It was there that I remember meeting her. We were part of a group that hung out together between sessions. We kept meeting at the same conference for several years. Besides hanging out, she would accompany me to the local pharmacy to pick up the prescription I had forgotten to bring with me. At least once, she even paid for it. Somehow, she still understood that I'm a competent adult.

We had fun together from the moment I remembered meeting her. We still do.

Clearly, I married up. I married my best friend. Joan is a picture of God's grace to me. Nobody knows my baggage better than she does . . . except Jesus. And they both still love me.

As you read, I hope you'll laugh at many of our stories—as we do. If you wonder if the stories are real, they are. And yes, I encouraged Joan to tell these stories with my blessing, even the ones about me. But after you shake your head and laugh, I hope you'll look again at the truth behind the story.

Joan is my primary caregiver. Growing up with a disability, I learned to be independent. But I'm faster when I have someone to help me physically. Some of our friends who also live with disabilities in the family say that the spouse should never be the

caregiver. For others like us, it works. Caregiving in marriage is a personal decision.

No one will care for me in quite the same way, or as well, as Joan does. She assists me with getting up in the morning and going to bed at night and lots of other tasks in between. Sometimes she's my physical therapist, advocate, chauffeur, . . . and the list goes on. No wonder she found it difficult to carve out time to write.

We still talk about hiring attendants. And I continue to drag my feet (funny how I can do that when they sit on the footrests of my wheelchair). There's a day coming soon when we will use attendants. But, I repeat, no one will care for me in quite the same way, or as well, as Joan does.

We also do ministry together. To learn more about our work, please visit Luke14Exchange.org.

We've learned to be intentional about dating and keeping our marriage strong. There are seasons when we do better with this than others. Joan and I know keenly that our marriage is still a work in progress. We're blessed that we share a lot of laughter—and an occasional tear along the way.

Early readers suggested that this book would be helpful for any marriage. That may be true. But Joan wrote this book with you in mind—for couples whose marriage includes disability. You are our tribe.

Enjoy.

Jerry Borton

INTRODUCTION

We were four years into marriage when we met Frank and Julia Burnett. They were members of a church we visited. Then in their twenty-third year of marriage, challenges overwhelmed them. While engaged, they had dreamed of serving together in full-time church ministry after he graduated from Bible college. Those hopes vanished just six weeks after their wedding. Frank was in a horrendous auto accident that left him with seizures, a brain injury, and multiple physical disabilities. Julia was his sole caregiver.

Now, after we had visited the church again, Julia invited us to come to their home the following Sunday for lunch. Over store-bought chicken salad sandwiches, potato salad, and coleslaw, they told us, “You’re the first couple we’ve met who live with disability in your marriage.”

What? They had already been married five times longer than we had. How could they never have met another couple like them?

Though they felt accepted and loved by their fellow church members, Julia and Frank also felt isolated and misunderstood.

That afternoon the loneliness and pain of twenty-three years tumbled out.

I wrote this book because of the Burnetts. I never want to hear of another couple who lives with disability in their marriage and knows no one else like themselves. We all need role models and mentors. Jerry and I are not perfect. And we certainly don't have all the answers. We may never meet you in person, but it is our hope that, by reading parts of our story, you may feel less alone.

There are three sections to this book. Section One details my understanding of what the Bible says about marriage. These principles are no different for couples with disabilities than for others. But I believe that these elements build the foundation for all that follows.

Section Two deals with many of the day-to-day scenarios disability throws our way. The manner in which Jerry and I address these may vary from the approach you and your spouse take. That's great. I share our stories and some questions we've pondered to kick-start your thinking, not to imply that they are the right or only way.

I wrote Section Three for the surrounding community. Chapter Thirteen seeks to create understanding for those who don't live with disability but know someone who does. The final chapter is for singles who wonder, because of their disability, whether they will ever get married.

Each chapter ends with two sets of *Embracing* points (variously worded). The first set is for the couple living with a disability in their marriage. These questions facilitate conversation between you and your spouse. The second set, *Embracing Your Friends*, is for the nondisabled reader who wants to know how to support their friends with disability.

If you need counseling and help with your marriage on a deeper level, please reach out to a pastor or therapist in your community. If you have trouble locating one, please reach out to me, and I will network to help you find one.

I pray for blessings on your marriage as you forge ahead to embrace the richness of a marriage affected by disability.

SECTION ONE

**ELEMENTS
OF A BIBLICAL
MARRIAGE**



ONE

BECOMING ONE

Two equals one? Although the modern education system uses a new system to explain math, the concept of two equals one seems counterintuitive. But in Matthew 19:4–6, the Bible says, “Haven’t you read,’ [Jesus] replied, ‘that at the beginning the Creator “made them male and female,” and said, “For this reason a man will leave his father and mother and be united to his wife, and the two will become one flesh”? So they are no longer two, but one flesh. Therefore what God has joined together, let no one separate.”

Couples often incorporate visual symbols into their wedding ceremony. Two popular ones are the lighting of a unity candle and the pouring of colored sand to represent the merging of their lives. These symbols offer some understanding, though the actual process of two people becoming one is more challenging and time-consuming than can be implied by a simple gesture. Genuine oneness begins with emotional and spiritual unity. It requires a conscious choice from each person to set aside their own agenda

and preferences for the sake of the other. Spiritual agreement involves the mystery of yielding control and authority to God.

Becoming one is a journey, a lifelong process. Even with almost three decades of marriage behind us, there are moments when Jerry and I still gaze at each other and wonder, *Where did you come from? Do you truly know me?*

Jordan Sok, a young married man, wrote, “I mean that just like metal . . . being melted to fit with another metal, marriage breaks down areas of your life that have never been broken down before. And that process is painful.”¹

But within this relinquishment lies a beautiful revelation. Becoming one with my husband means that his challenges are mine, and mine have become his. We share not only the burdens, but also the joys of life. Neither of us has to face a situation alone. What one of us does affects the other. Our lives are interdependent. Jerry often says, “I can’t believe that, other than God, Joan is the only person who knows my stuff and still loves me.”

Being one doesn’t imply a lack of disagreement, enjoyment of the same activities, or identical thought processes. In fact, as I write this, we find ourselves in a humorous miscommunication. While I’m at the public library, Jerry is in his home office. Our attempts to communicate via text and email have failed to convey our intended messages. Frustrated, I finally gave up and called him. If only oneness included mind meld.

When two become one, life can no longer be solely about oneself. However, this doesn’t mean that we are to ignore personal development or make our spouse responsible for everything. I no longer live, think, or act solely on the basis of *my* desires. Instead, our operating system revolves around considering each other’s needs and desires. Becoming one is a *we* endeavor.

At the time of our first anniversary, we attended a marriage conference called Family Life Weekend to Remember. One exercise the speaker led involved facing our spouses and declaring, “We are Jerry and Joan Borton, another one of God’s great ideas.” Although this may sound amusing, the statement holds truth. We periodically remind ourselves of this and often open sessions we teach on marriage with this affirmation.

We celebrate our unique gifts, skills, and talents and look for opportunities to use them, perhaps together. Blending our strengths creates a united purpose for our days, our energy, and our focus. Together, our aim is to bring glory to God, to love one another, and to encourage individuals and families affected by disability.

Prayer is one way to grow in oneness. I hear my husband’s heart when we pray together. I cherish the time we sit face-to-face or side-by-side and approach the throne of God. We pray for our days, our finances, our ministry, and each other’s personal battles. We also pray for friends and family. For many years we saved the Christmas cards we had received. Each night after dinner, we selected two and prayed for those friends.

Scripture tells us that, where two or more gather in the name of Jesus, he is there (Matthew 18:20). When one of us travels for business or we spend a day apart, we often pray together by text, email, or phone. Sharing with God and each other what is uppermost on our hearts and minds deepens our understanding. Even when we stumble over words, placing our praises and petitions before our Lord increases our experience of oneness.

Oneness also includes physical and emotional intimacy. Chapter four will go into this in more detail. Spending quality time and sharing both daily life and special occasions together

can also increase the sense of oneness. Often couples want this but struggle with the how-to. Chapter eleven has many suggestions for dates and celebrations.

When I drop something or my poor coordination takes center stage, we joke that CP must be contagious. Of course, it is not. Yet I have to embrace Jerry's disability in order to be one with him. Fighting against it, ignoring it, or overcompensating for his disability detracts from our unity. Suzanne Mintz, founder of the National Family Caregiver's Association, describes her life with Steven, diagnosed with multiple sclerosis (MS), like this: "He has clinical MS, but we both have MS."²

Whether you or your spouse had a disability when you married or acquired one afterward, oneness remains God's standard.³ There is no biblical exemption for couples living with disability. As with other parts of a marriage including disability, oneness may look different in your marriage than in mine—it probably will. And that's okay. Thankfully, we're not the first ones to walk this road. But we have the perfect role model for our journey. Peter Rosenberger dedicated his book *Hope for the Caregiver*⁴ to "Jesus Christ, Ultimate Caregiver to the Wounded Bride."

In this description of Jesus caring for us, we see one blessing in a marriage that involves disability. We have the beautiful privilege of being a living example of the love Jesus Christ has for his Church. Through our relationship, others will see how Jesus cares for, loves, and serves his body. They will observe how an imperfect body responds to love.

The apostle Paul tells us in Philippians 2:3–4 how to follow Christ's example. We are called to look not only to our own needs but also to the needs of our partner. Consider how our actions

and thoughts may affect them. Act and speak to build up the person and the relationship.

The world of disability is open ended. Every person is one step, one breath, one heartbeat away from joining our ranks. Our growth in oneness shows the world that it's possible to not only survive but to thrive in a marriage that includes a disability.

While Isaac and Jill parented children with medical needs, their hands were full. They never expected that, a few years later, disability would also enter their marriage, but it did when Isaac received a diagnosis of multiple sclerosis. Now, over twenty years later, they share some things they learned about becoming one:

Jill: "Everyone should know we are on each other's team. There is no doubt we support each other, and people know we are there for one another. Allow the gift of loyalty to show through. See the value in each other. Live in an understanding way, even if you don't understand it. I don't have to get whatever is happening with Isaac, but I have to be understanding and kind because that's what Jesus would do."

Isaac: "We live a new normal, not like others. Not worse, just different. Sometimes in the crazy marriage cycle of ups and downs, it's hard to think the best about your spouse. As a man, I may hear my wife's helpful comments as criticism. I need to remember that she has my best in mind. Don't let the *D* word (divorce) enter your conversations. My diagnosis reminded me of our vows to love each other in sickness and in health. There were times I thought she'd be better without me, but marriage is a together commitment."

EMBRACING ONENESS

1. Set aside time to assess your oneness. How have you grown in this over the years? What still needs to develop? Face each other, and, using your own names, say together, “We are _____ and _____, another one of God’s great ideas.”
2. Have you and your spouse talked about the purpose of, or a vision for, your marriage? If not, set a time to explore this.
3. Do you pray together? What one step could you take to deepen your prayer life with one another?

EMBRACING YOUR FRIENDS

1. Don’t lower expectations about marriage for your friends with disabilities. Encourage them to live and love according to the Bible’s model.
2. Marriage is hard, and disability is relentless. Encourage your friends by positively mentioning the ways you see them becoming one.
3. Pray for your friends’ marriages. You don’t need to tell them. Just pray.

GENESIS 2:23-24

“The man said, ‘This is now bone of my bones and flesh of my flesh; she shall be called “woman,” for she was taken out of man.’ That is why a man leaves his father and mother and is united to his wife, and they become one flesh.”

PRAYER

Thank you, God, for my spouse. Thank you for the unique way you knit us together as individuals and brought us together in you. Show us how to deepen our life and love with each other and show you to the world around us. Amen.