

CONTENTS

List of Worksheets xi

Foreword xiii

Lawrence D. Rosen, MD

Acknowledgments xv

The Unexpected Journey Begins 3

Why We Wrote This Book 6

What's in This Book 7

Our Stories About Chronic Illness 11

Our Hopes for You 18

Chapter 1. Navigating Your Feelings 21

What Is Chronic Illness? 23

*Your Feelings Are All Over the Map—
And That's Normal* 24

How to Cope With Your Feelings 39

Next Step: Hope Helps You Cope 43

<i>Chapter 2.</i>	<i>Staying Healthy on the Journey</i>	<i>49</i>
	<i>Burnout and Compassion Fatigue</i>	<i>50</i>
	<i>Exploring Mindfulness Paths</i>	<i>55</i>
	<i>Exploring Spiritual Paths</i>	<i>68</i>
	<i>Next Step: Make Humor Part of Your Every Day</i>	<i>77</i>
 <i>Chapter 3.</i>	 <i>Getting What You Need On the Road to the New Normal</i>	 <i>83</i>
	<i>“I Don’t Have Time for One More Appointment!”</i>	<i>85</i>
	<i>Finding a Therapist</i>	<i>86</i>
	<i>Support Groups</i>	<i>92</i>
	<i>Working With Your Insurance Company</i>	<i>95</i>
	<i>Working With Your Employer</i>	<i>101</i>
	<i>Be Persistent and Insistent</i>	<i>103</i>
	<i>Finding Child Care and Respite Care</i>	<i>106</i>
	<i>Next Step: Consider Participating in Clinical Research</i>	<i>109</i>
 <i>Chapter 4.</i>	 <i>Communicating With Your Child: It’s a Two-Way Street</i>	 <i>113</i>
	<i>Breaking the News to Your Child About Their Illness</i>	<i>114</i>
	<i>Managing the Booster Seats: Talking With Your Preschool-Age Child</i>	<i>117</i>
	<i>Teaching Them to Buckle Up: Talking With Your School-Age Child</i>	<i>122</i>
	<i>Driving Lessons: Conversations With Your Teen</i>	<i>129</i>
	<i>Next Step: You Can’t Always Fix It, but You Can Be Present</i>	<i>140</i>

<i>Chapter 5.</i>	<i>Your Copilots: Other Parents and Parent Figures in Your Child's Life</i>	<i>145</i>
	<i>Staying Calm at the Wheel</i>	<i>146</i>
	<i>When You're Driving Alone</i>	<i>156</i>
	<i>Sharing the Wheel: When You Are in a Committed Relationship</i>	<i>157</i>
	<i>Taking Turns at the Wheel: When You're Separated or Divorced</i>	<i>162</i>
	<i>Next Step: Get That Engine Running More Smoothly</i>	<i>167</i>
 <i>Chapter 6.</i>	 <i>Getting Everyone on Board: Siblings and Other Family Members</i>	 <i>173</i>
	<i>Bringing Siblings on Board</i>	<i>175</i>
	<i>Bringing in Grandparents</i>	<i>186</i>
	<i>Stepparents: Where Do You Belong—Back Seat or Front Seat?</i>	<i>188</i>
	<i>Next Step: Be Family Focused Rather Than Illness Focused</i>	<i>191</i>
 <i>Chapter 7.</i>	 <i>Mechanics of Working With the Medical Team</i>	 <i>199</i>
	<i>Who Is on Your Child's Medical Team?</i>	<i>200</i>
	<i>Communicating Effectively With the Medical Team</i>	<i>201</i>
	<i>At-Home Treatments and Medications</i>	<i>216</i>
	<i>Making Pills More Manageable</i>	<i>226</i>
	<i>Needle Fears: A Stick-y Situation</i>	<i>229</i>
	<i>Next Step: Giving Your Child More Responsibility for Health Care Communication</i>	<i>233</i>

<i>Chapter 8.</i>	Mechanics of Working With the School Team	237
	<i>Civil Rights Laws That Support Your Child</i>	239
	<i>The On-Ramp Back to School</i>	247
	<i>Other School Avenues</i>	248
	<i>When Your Child Refuses to Go to School</i>	256
	<i>Dealing With Stigma</i>	260
	<i>Bullying</i>	262
	<i>Next Step: Take Action Against Disability Harassment</i>	263
 <i>Chapter 9.</i>	 The Cone Zone: Setting Healthy Boundaries	 265
	<i>Mindful Listening and Talking</i>	267
	<i>Letting Others Know What You Need</i>	279
	<i>Next Step: Help Your Child Set Healthy Boundaries With Others</i>	282
 <i>Chapter 10.</i>	 When Your Journey Includes Hospital Stays	 285
	<i>Gathering Information</i>	287
	<i>Preparing Your Child—And Yourself</i>	290
	<i>In the Hospital</i>	293
	<i>Dealing With Medical Procedures</i>	301
	<i>Next Step: Learn About Comfort Care</i>	312
 <i>Chapter 11.</i>	 The Journey Through Death and Beyond	 317
	<i>Making Impossible Decisions</i>	318
	<i>Coming to the End of the Road</i>	325
	<i>Next Step: Building Your Child's Legacy</i>	337
 <i>Chapter 12.</i>	 Concluding Thoughts: Building Resilience on the Journey	 339
 	 Resources for Your Journey	 343
 	 Notes	 369
 	 Index	 395
 	 About the Authors	 417

THE UNEXPECTED JOURNEY BEGINS

When your child was diagnosed with a chronic illness, your life turned upside down. Your picture of the life you thought you would have turned upside down too. And now, whether you are mere days from learning of the diagnosis or several years down the road, you probably have some days of smooth sailing and some days when you're nothing but stressed out. You know that at some point you will find a new normal, and you know that your struggles will develop your strengths. But in the meantime, you're asking yourself: "Where will this journey take me next?"; "I wish I knew all the possible detours so I could plan for them"; "Are we there yet?" You knew you were in for a ride when you became a parent, but you weren't counting on this many bumps in the road!

What is obvious for you now is your calendar of appointments. Does it look something like this?

- Monday, 3:45: Take child for a blood draw
- Tuesday: Meet with child's teacher to discuss making up assignments
- ASAP! Call insurance company to make sure they'll cover the next procedure

On Saturday you had scheduled a coffee date with a friend—but you have to skip it. You need to take an extra shift at work because your coworker covered for you last week when you had to miss so you could keep your child at home during a flare-up of the illness.

Most likely, you are already a pro at navigating certain parts of the chronic-illness journey. You've learned that your child's health needs often dictate where you will be and when. You also have a set of map coordinates, so to speak, that keep you focused when you perform procedures you never thought you'd need to do—for example, monitoring your child's blood sugar and treating urgent highs and lows, or executing airway clearance techniques you learned from the respiratory therapist. You can tick through a symptom checklist in seconds to determine whether a nurse consult over the phone or a visit to the emergency room is in order.

You are doing an amazing job. You are parenting the very best you can—even if the view through your windshield looks different than you thought it would. Your amazing love for your child is enough to power you through most days.

Other days, you feel lost.

Where are all these emotions coming from? Why am I suddenly angry for no reason? Some days, I am so exhausted it is hard to get out of bed. It kills me to see my toddler crying when I can't help him. And why can't my teen take this more seriously? At times it seems like she doesn't care!

If you are feeling lost in uncharted territory, know that you are not alone: You are part of an enormous community. Estimates of the numbers of children with chronic illness range from 15%¹ to 31%,² with some estimates as high as 43%.³ Estimates may vary depending on which conditions are included; autism, for example, may be counted as a chronic illness even though it is a type of neurological

condition that we do not address in this book. Still, this means that in your child's class of 20 there may be two to eight other children with some kind of chronic illness or condition.

Many of these illnesses and conditions were once fatal, or condemned children to a very short life, often full of suffering. The good news is that, with the amazing advances of medical science over the past decades, new treatments have been found that greatly prolong the life and enhance the well-being of children with chronic illnesses. The challenge is that these new treatments can't always cure the disease, and the additional work of caring for children has shifted from the medical community square onto the shoulders of their parents. That's you.

You've probably seen firsthand how, as a society, we keep our sick on the sidelines, out of our everyday awareness. We even act as if they are some other species of human. This makes them and their families invisible. In the parallel universe of chronic illness, you may feel there are no familiar markers. You're meeting a new, strange cast of characters. People you thought would be with you through thick and thin have disappeared, while others you may barely know have stepped up in ways you never imagined. Your relationships seem to be changing every day! You feel like you're cutting a path through the wilderness.

In reality, though, there are some paths, well-worn ones. You don't have to stumble around in the dark. Maybe you've met other families who have been through a chronic illness journey. Their path won't be exactly the same as yours; each family's journey is unique. Still, the paths are there. Others have felt how you are feeling right now. Others have gotten stuck in the same ruts as you. Others have traveled the rocky relationship road, too. And guess what—some of them even left a few notes in the logbook to help you out.

WHY WE WROTE THIS BOOK

Chronic illness isn't a journey we expect or plan to take with our child, but sometimes that is what life hands us. We wrote this book because we, the authors, know from our own experience how confusing and challenging this journey of chronic illness can be, but we also know that families can meet those challenges, and even thrive in the face of them. Frank has an autoimmune disorder called Crohn's disease. Carol cared for her husband through his cancer, until she had to say goodbye to him. In our professional lives, we both work with children and families to help them learn how to deal with the emotions and relationship challenges that chronic illness can bring. One of the things we've both learned is that it's impossible to chart a course for this journey on any kind of map—not even the kind that computes real-time data and works on your smart device. The other thing we've learned is that there are options for finding your new normal and navigating your life besides having to feel your way through the narrow places and over the bumps all on your own.

On the chronic illness journey with your child, there are potholes aplenty, but there are also some excellent pit stops and scenic vistas. Your emotions, your relationships, and your needs for self-care are all real—just as real as the medical facts you see in black and white. They are as real as the physical needs your child has. We wrote this book to help you see these hidden parts of the journey.

So many things drain your energy: strong feelings, tough choices, not to mention the sheer volume of calls you make and texts you write daily to maintain your support system. Our hope with this book is to help you save some of that energy. The learning curve is steep, but we hope to level it out a bit for you. In this book we share some need-to-know facts from the scientific research on parenting and chronic illness. We also share the wisdom from

journeys of other families with childhood chronic illness. We want you to be able not only to cope but also to feel confident, engaged—and, yes!—happy, as your parenting life continues to unfold.

WHAT'S IN THIS BOOK

This book is intended primarily for parents who have a child age 3 through 17 with a chronic illness. We say age 3 instead of infancy because many of our tips are about talking with your child and setting expectations and boundaries that go beyond such basics as sleep, eating, and diapering/toileting (though these life tasks are always relevant in different ways and at different developmental stages). Many excellent resources are available to parents with an adult child who is living at home or who is transitioning to independent living. We recommend starting with websites of pediatric hospitals and care facilities to learn more. Some helpful websites include <https://luriechildrens.org> (search for “Transitioning to Adult Care” under the “Specialties and Conditions” tab), <https://arnoldpalmerhospital.com/content-hub/how-to-transition-your-child-with-a-chronic-illness-into-adulthood>, and <https://childrens.com> (search for “Transitioning to Adult Care”).

In putting this book together, we wanted to mirror the process of a journey, starting with the immediate effects of your child’s diagnosis. We offer the information in a somewhat chronological order, starting with your first knowledge of the diagnosis and the steps we recommend taking first. You might be surprised that the first several chapters are focused on you, the parent. This is because your first responsibility—even in parenting or a couple relationship—is to take care of yourself. If you’ve ever been on an airplane you know what the flight attendant says to do with the oxygen mask, should it deploy: Put one on yourself before trying to assist others. If you can’t breathe, you are no good to anyone else.

In Chapter 1 we discuss the range of emotions you might be feeling now or in the future, and we offer a few healthy tips for coping. The same emotions will arise again and again, often in roller coaster fashion, so being able to recognize, deal with, and express them appropriately will be key to reducing your stress. In Chapter 2 we demonstrate how to be compassionate to yourself, and we guide you through some self-care options to help build your resilience.

Chapter 3 is all about channeling that resilience and the dreams you have for your family into getting what you need, whether that be a support group or respite care. We also address some of the rubber-meets-road decisions you may need to face, such as whether or not quitting your job might be in your family's best interest. We expect that, as your journey unfolds, your needs as a parent and as an individual will change. At some point you may want to use therapy for psychological support, either for yourself, particular individuals in the family, your couple relationship, or the family as a whole. So, in addition to positive coping strategies, we also highlight in Chapter 3 some red flags that could indicate the need for psychological support, and we describe how and where you can find it.

As you learn more and more about your child's diagnosis, you will not only need to talk with your child about the illness, but you may also need to learn new ways of listening to your child. Chapter 4 covers this in detail. Chapter 5 then turns to your copilots on the journey. Whether you are parenting alongside your spouse, an ex, your own parents, in-laws, or others, effective communication skills come in very handy, especially when emotions run high. In Chapter 5 we explore how to have good, productive conversations, and we present ideas for strengthening your emotional connections with others close to you. Chapter 6 covers important conversations to have with siblings and other family members as well as tips for maintaining a family focus even when many of your daily activities are oriented toward your child.

Chapter 7 is all about working with medical professionals to make your child's journey as smooth as possible. They play a crucial role in keeping your child well and happy. We show what advocacy and self-advocacy can look like for your child, both in the clinic and when treatment continues at home. We also discuss helping your child with swallowing pills and coping with needles.

In addition to medical personnel, families often need to communicate with school personnel: teachers, aides, school psychologists, and others. Chapter 8 describes how to obtain support or special-needs services at school, how to work through other school-related issues (such as bullying), and when to consider whether homeschooling might be the best route.

Chapter 9 offers boundary-setting skills that you can practice with coworkers, acquaintances, or others with whom you don't regularly share details about your family's situation. For example, how can you be both honest and civil when others offer their support in the form of unwelcome advice?

Perhaps the most challenging aspect of having a child with a chronic medical condition is hospitalization. In Chapter 10 we address the potential disruptions of a hospital stay. We also provide helpful coping tools for easing your child's discomfort during difficult procedures.

Chapter 11 explores the ways the family changes when a child dies as a result of chronic illness. Here we offer some practical guidance for end-of-life conversations and resources for dealing with grief.

Chapter 12 provides a brief summary of the book and some encouragement as you continue on your parenting journey.

Toward the end of the book we include a part called Resources for Your Journey, which lists children's books, organizations, and apps that may be helpful.

Throughout each chapter we provide practical tips, geared toward your child's age or developmental stage, for managing

emotions, communicating effectively, and building relationships. We end each chapter with a list of actionable ideas to help you think about next steps you will take toward making the best of your family's journey. In many chapters we've also included stories or quotations from real life. We hope that hearing what our patients have said, and learning how they found solutions or ways to feel better, will inspire you to keep reading. Where we describe or quote individuals, please note that we have changed names and other identifying details to protect their privacy.

We have used as our foundation both the scientific research literature and our own clinical training and experience. Fortunately, the research now includes, in addition to more formal quantitative research, valuable qualitative studies, which highlight major themes in the actual lived experience of families with a child who has a chronic illness. Quantitative research, which deals with groups as a whole and shows us patterns of what interventions affect which outcomes, is also valuable. Please note, however, that no intervention or treatment described in the research yields a 100% response; that is, although well-designed studies tell us a great deal about groups of people, they cannot tell us definitively what is happening for a particular individual or a particular family. Even in studies where large effects are found—say, 30% or 40% or more—that means a difference was made in only 30% or 40% of families. The other 60% to 70% were unaffected.

In brief, when considering treatments for your child, you have to rely on your own knowledge of your family and of what is best for everyone. Your family's culture and background, your resources, and your context will influence how you see the issues and what you determine is the best course of action. All that we offer here, although solidly based, are possibilities. We ask that you read what we offer with an open mind and then reflect on what makes sense for you. We trust your judgment to determine the right course of action for your family.

You'll notice that throughout the book the pronouns we use shift. Sometimes we refer to "they and them," sometimes to "she and her," sometimes to "he and him." This was intentional! Language matters, and we want ours to be inclusive, so that many readers can relate to the material and see a bit of their own situation in the stories we describe.

OUR STORIES ABOUT CHRONIC ILLNESS

All chronic illnesses have their own unique characteristics. Some may have a trajectory with many ups and downs, ranging from acute symptoms to remission to a return of even more acute symptoms. Some people may eventually develop a terminal illness. Others' condition remains pretty steady, with a greater degree of predictability and consistency of symptoms. Two people with the same illness can even have vastly different experiences—for example, in the way their bodies respond to medications or to a special diet.

We point this out because it can sometimes be hard to listen to others' stories if the specifics are different from your own. "Well, *they* have partners who can come home early to cook!"; "Well, kids with *that* condition don't have to worry about missing months of school!" It's tempting to react this way sometimes, but we want to encourage you to open yourself to others' experiences. Look for what is similar in their stories. Some feelings are universal. Take what is helpful to you, and shelve or discard the rest. Stay on your own path. For a little insight into our personal journeys, read on.

Frank's Story

A little over 30 years ago, my life changed in two ways. First, I was accepted to the psychology graduate program at Fordham University

in New York City; I was on my way to a career as a psychologist. Second, I started to have gastrointestinal problems.

I was 22 years old at the time—younger than most of my classmates—and although I was excited, and honored, to be admitted to a program that admits a limited number of students each year, I was equally petrified about the mountains of work and time that came along with graduate studies. I also had to get acclimated to commuting into New York City, taking buses and subways. Believe it or not, despite living in nearby New Jersey, I had little exposure to the stress of public transportation.

About halfway through my first year, I started to have gastrointestinal problems. Any time I ate, food ran through my system like a rocket ship. I could not keep any food in my system. I lost a tremendous amount of weight, and I looked, and felt, ill. Everyone, including me, thought my symptoms were from the stress caused by beginning graduate school.

Eating seemed to become my enemy. Meals were always followed by a sprint to the bathroom. There were several instances when I was on the public bus going to school when I would feel sick and no bathroom was in sight. This caused me tremendous anxiety. I was in constant fear that I would soil myself. I couldn't leave the house in the morning before feeling completely emptied out. There were many instances where I left only to return minutes later to use the bathroom. I was "bathroom stalled."

Although people in my life were supportive, I was often met with, "It's all in your head," "You're just stressed out," and "My gosh! You're so thin! Put some meat on those bones!" I also dealt with a lot of insensitive diarrhea jokes. I wasn't laughing. I was feeling hopeless, defective, and depressed.

What followed next was a series of appointments with several doctors for various opinions. Was it irritable bowel syndrome? Inflammatory bowel disease? With the doctor appointments came

many different tests and procedures. I had blood drawn over and over. I felt like a pincushion. I had multiple upper and lower GI (gastrointestinal) tests done. I had numerous sigmoidoscopies, colonoscopies, CT (computed tomography) scans, parasite tests, stool tests, and MRIs (magnetic resonance imaging scans). I drank barium solutions that tasted like chalk and made me gag. The prep for the colonoscopy was dreadful. I even had a pill camera test in which I swallowed a pill with a miniature camera in it. I had to wear a vest that was hooked up with electrical equipment so that pictures can be taken as the pill traveled through my body. I looked like a terrorist. All of these tests and medical appointments meant taking time off, sitting endlessly in waiting rooms, driving all over the New York City region, being probed in uncomfortable places, and repeating my story over and over. Some of the medicines prescribed actually made my symptoms worse or just made me feel worse in general—more exhausted, more stressed out.

As time went on, I lost more weight and continued to feel horrible. I would look at myself in the mirror and not recognize my own reflection. I was appalled at my appearance. Clothes hung off my body. Despite being sick, I never missed school and continued to work diligently on my doctoral degree. Nothing was going to stop me.

After about a year or so of back and forth with doctors, tests, and medications, I finally received the diagnosis of Crohn's disease. Crohn's is an autoimmune disease that affects the gastrointestinal tract anywhere from the mouth to the anus. My Crohn's was at my terminal ileum, which is the point at which the small intestine meets the large intestine. Because I had so much scar tissue in that area due to Crohn's, my terminal ileum became narrowed. If I ate certain foods, like raw vegetables or nuts, it blocked the opening, which caused tremendous pain, nausea, vomiting, and emergency room visits. Although I was relieved that I now had a name and a

treatment option attached to what was happening to me, I still was not myself. I struggled with diarrhea, low-grade fever, fatigue, and weight loss, among other symptoms.

I popped antidiarrheal medication like Tic Tacs. I found that turkey was easy on my digestive system; however, I ate so much turkey I swore I was going to grow feathers. At times, I pureed my food and ate baby food to give my bowels a rest. This helped, but it made going out for dinner and socializing extremely challenging. I watched my diet, and at times restricted my intake of food: No food, no diarrhea. This was not a healthy approach to my disease or to living, but I didn't know what else to do.

In 1995, after 6 years of studying, doing externships, an internship, writing, defending a dissertation, and a multitude of other hurdles, I graduated from Fordham with my PhD in counseling psychology. At that time, I was the youngest person to graduate with a doctorate from Fordham's counseling psychology program. I had started working in my field and began a small private practice. I started working therapeutically with children, adolescents, and adults. I loved my work as a psychologist but continued to have periodic flare-ups with Crohn's disease. I went to my doctor regularly. I also sought out treatment from alternative doctors. In the early to late 1990s, alternative medicine and treatments were rare and not as well respected as they are today. Still, I would do anything to feel better. I kept persevering in my career and worked full time while maintaining a part-time private practice of about 15 patients a week. I was busy.

At that time, my professional work mainly involved helping children deal with issues related to divorce, feelings of anxiety and depression, or bullying incidents at school, among others. I wanted to do something for myself and others who had Crohn's disease. I joined the New Jersey chapter of the Crohn's and Colitis Foundation and started getting involved as a board member. I participated

in walks and fundraisers. I was also starting to get asked to speak to various chapters across the country about the psychological aspects of chronic illness.

I eventually began to get referrals in my practice of children, adults, and families struggling with chronic illnesses, in particular gastrointestinal diseases. The kids started to call me “Dr. Gutsy.” In working with the children in my practice, I use a therapeutic technique called “bibliotherapy.” Child bibliotherapy involves reading a story about a particular problem to a child. The story helps them understand the problem, validates their thoughts and feelings, and offers healthy coping tools and solutions. During a session with a young girl who had Crohn’s, she said to me, “How come there are no books on Crohn’s disease for kids?” This got me thinking.

I started writing a children’s book, and in 2005 my first book was published. It was called *Toilet Paper Flowers: A Story for Children About Crohn’s Disease*.⁴ This book launched further speaking engagements and became the genesis of my writing career as a children’s book author in addition to being a psychologist. The speaking engagements across the country, and that first book, are what I view as making lemonade out of lemons.

Being diagnosed as an adult was difficult. Having gone from being a healthy individual to one who was ill with restrictions really presented me with challenges. I have learned a lot from my patients, however. I love listening to and helping my patients, especially when the young ones share their stories of what it was like to be diagnosed as a child. I remember a boy I met at a walk for Crohn’s and colitis. His name was Joe, and he was about 5 years old. He had a tremendous spirit and an enthusiasm for life. When I asked his mother how Joe felt about having Crohn’s, she told me, “It’s all he has ever known. He doesn’t know any different. He had to accept it from the day he was born.” That put things into a different perspective for me. I still think about Joe from time and time and hope he is doing well.

When I am doing speaking engagements across the country, it is amazing to me to discover that although my disease and the disease the audience members have is the same, our journeys may be completely different. So many factors in one's life can change the journey. What is constant in my therapeutic work and through meeting people across the United States is that everyone struggles with the same feelings and has similar questions. We all share the same humanity. We are all vulnerable and brave. We are tired but we continue to fight. We feel hopeless, but somehow we continue to put one foot in front of the other. We feel alone and want to connect with others.

All the parents I meet want to be the best parents to their children, to give them everything in life, with the ultimate goal of being well. Every day, I meet courageous children and adults fighting for a better day, a cure, a breakthrough. This book, about parenting children with chronic illness, has been something I have wanted to write since I began my therapeutic work with children and families who are affected by health conditions. I fervently hope that you and those in your life can not only learn from the pages that follow but also discover things from each other and realize that we are not alone on our journey for our kids and for ourselves. Never give up. I wish you health and peace in your lives.

Carol's Story

I remember vividly the moment when my life split in two. It was late morning on Monday, October 19, 1987. For many, it was called Black Monday because of a sudden drop in the stock market, but it has an entirely different meaning for me.

I had been visiting my agent, talking about going back to work now that my son was 3 months old. My husband had been having some medical issues, and we had spent a harrowing weekend

waiting for the results of a test he had done Friday. I met him for coffee down the street from my agent's office, so he could tell me what was going on. And I heard the words no one wants to hear from someone they love: "It's lung cancer," he said.

A sob of anguish and disbelief sprang out before I could stop myself, and he immediately let me know that he needed to be able to lean on my strength. I pulled myself together, offered him some words of encouragement, and watched as he drove off with a friend to see the oncologist.

When I looked up, my whole world had changed. Everything looked the same, and yet nothing was the same. The streets, the cars, the trees and street signs, even the sun shining in the open southern California sky—suddenly, nothing felt familiar. In the weeks and months that followed, I found myself in a parallel universe of doctors' offices, pharmacies, and hospitals, a world that exists side by side with our everyday world but that is invisible to most of us, until we find ourselves dealing with the unthinkable.

I remember the stress of having to fill a prescription at the last minute, one of those triplicate prescriptions that could not be filled by phone but required a trip to the doctor's office to retrieve a hard copy and a wait at the pharmacy while it was filled, assuming they had the medication on hand. With all the other aspects of life to manage, I was often unaware that the medication had run out, but it needed to be filled *today*.

There were long, painful conversations with doctors about what treatments were available, and misunderstandings galore. When my husband and I would go over what the doctor said, we often had entirely different versions. His pessimism unnerved me, and I am sure my stubborn optimism left him feeling unseen in some important way. Juggling the needs of a new baby and a sick husband stretched my capacities to the limit, and although I appreciated the concern of our friends, the constant task of keeping people up to date exhausted

me, to say nothing of the pain of having to repeat bad news to one friend after another.

The illness of a family member affects everyone in the family and has ramifications for how each family member engages with her world. Relationships are altered, interrupted by medical emergencies, and sometimes put to the side to tend to the needs of the ill person. These lost periods may be difficult to reclaim.

There was, however, another aspect of this time that surprised me, fulfilled me in a way I never would have imagined: a sense of mission. I felt something like a calling to be caring for my husband at this time. My life had a very particular, significant—and yes, I would say, sacred—meaning that helped me persevere despite the sadness, the fatigue, the unpredictability. Not only did he need me to do for him what he could not do for himself, but also everything I did served as balm to soothe him, relieve his pain, help him sort out his own meaning. It felt like a tremendous honor.

OUR HOPES FOR YOU

This may sound strange, but one of our hopes for you, the reader, is that you can skip over some parts of this book completely! Perhaps you are already good at self-care, or at managing sibling relationships; your child may never need hospitalization or many of the procedures we talk about. We also hope that this book can shorten the learning time around the emotional and interpersonal processes you haven't had as much chance to practice. There will be times you'll feel proud of yourself and your family for how you are able to thrive and other times when you'll fall flat on your face. The worst part of that is feeling that you may be failing those you love. But then you'll get up again and keep going.

We are honored to share the findings of research and our own training and experience with you. We want to give you the tools you

need, first to understand that what you are going through is real and that your feelings are to be expected, and then to meet head on the challenges you are facing. We hope that through all the ups and downs, the times of quiet and the times of chaos, you will find a kind of crazy beauty in your life with fresher and deeper connections with the people around you, a greater sense of intimacy with your family, and, for all of you, a fuller appreciation for the enormous gift of being alive.

With that said, let's get started.