

Reprinted from *When Your Child is Sick* by arrangement with TarcherPerigee, an imprint of Penguin Publishing Group, a division of Penguin Random House LLC. Copyright © 2018, Joanna Breyer

This book is for parents of children who have medical conditions requiring hospitalization and lengthy treatments. You are facing an unexpected, enormously upsetting, and unwelcome challenge. Having a child in the hospital repeatedly or over time is emotionally draining and disruptive to family life, not to mention hard in many practical ways. How your children, ill and healthy, react to the hospitalization may also cause you stress and worry. My hope is that this book will offer advice to help you and your children through this difficult experience.

I had the privilege of working as a psychologist for twenty-five years at Children's Hospital Boston and in several outpatient clinics at the Dana-Farber Cancer Institute. I counseled children and adolescents who had cancer, as well as their families. Over the years, I got to know many children and families in the most trying circumstances. I often marveled at the parents' strength as their child's treatments progressed and at the children's resilience as they flourished, despite their illness. I learned how different children are and that what helps one child might not help another. I appreciated the younger children who sometimes protested loudest at what they were expected to endure, and I worked with their parents to discover which simple tools and interventions could transform their understandable outrage and opposition into cooperation, mastery, and pride. I came to admire the adolescents whose lives were so dramatically upset by their illness and treatments and wondered at the range of their responses. I also came to respect the strength and courage of parents. Although my experience was primarily in working with children with cancer and their families, I hope that much of what follows will be relevant to parents of children hospitalized for a variety of reasons, such as a sudden severe injury or chronic conditions like cystic fibrosis, sickle cell anemia, diabetes, or chronic cardiac conditions.

In the coming chapters, I will describe a range of reactions that children may have to their hospitalization and treatment and possible interventions that may be useful in your family depending on the age, character, and temperament of your child and your parental style. You, as the parent, are the expert on your child; you are with them, know them, and are best suited to communicate their emotional needs to the medical team working to help them. However, the hospital is a new world, and in this foreign context, particularly at first, you may not always feel you know what is best for your child or what he or she needs. You will likely feel tired, sad, and scared much of the time, and taking care of yourself may require a considerable effort. It may be hard to believe how such a place can quickly become familiar.

This book has three sections:

Part I makes the hospital world a little more familiar to you by describing the people you are likely to meet and what their roles are. I will outline some of the challenges you may encounter and offer some ideas that other parents have come up with for how to deal with them. I suggest ways to talk directly with your child about his condition. I describe children's and adolescents' varied reactions to the stress of hospitalization and invasive treatments and give examples of ways to help them cope with the new demands they are facing. I talk about responses your other children may have and about interventions to help them. I detail some of the challenges you, your child, and your child's siblings face if your child needs a stem cell transplant. Finally, I discuss some of the issues you and your family may face when your child returns home after a long hospitalization.

In Part II, I address issues of "survivorship" that you and your child may face after your child's treatment is completed. Because I worked for many years in a childhood cancer survivorship clinic, my emphasis in this section is on childhood cancer survivors, although much of what I discuss will be relevant to children who have lived with or are living with other serious medical conditions.

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Part III is for parents whose children are not healed by their treatments whatever their initial condition—who despite everybody’s best efforts, over time, quickly or slowly get worse and cannot be cured. This section acknowledges the many different styles and approaches of parents and children in this situation. I discuss ways to make direct conversations a little more bearable and ways that you can acknowledge the situation indirectly. This section encourages you to trust your instincts and find comfort in this heartbreaking situation in whatever ways you can. The final chapter describes different ways in which people grieve and ways parents have honored and remembered their child as time passes.

Other families’ stories are interspersed in boxes throughout the book. Many families generously gave me permission to quote part of their stories, and some children and parents have written directly about their experiences and how they would advise other parents. In instances when I could not reach a family I have changed their stories in ways to preserve their privacy. Although your story will be different, my hope is that it will be some comfort to know ways in which others have navigated this path before you.

My expectation is that different parts of the book will be relevant at different times, and my hope is that you will use the index and detailed chapter headings to find the topic of immediate interest to you.