When the Diagnosis Is Multiple Sclerosis: Help, Hope, and Insights from an Affected Physician

Kym Orsetti Furney, M.D.

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WHEN THE DIAGNOSIS IS MULTIPLE SCLEROSIS

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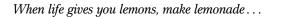
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A poster with these inspirational words hung on my bedroom wall throughout my adolescent years. With the naiveté of a child, I had assumed the phrase meant that I should make the most of the gifts I was given. In recent years, I saw that phrase emerge again. As an adult I realized that, of course, the lemons represented some sort of misfortune that should be transformed into something good. I laughed at myself for my innocent interpretation for all those years. Somehow, I now see this book as representing a product of both of my interpretations of those lemons.

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SERIES FOREWORD

I had the opportunity to meet Kym Furney at a medical conference that focused on publishing. This book was the reason that Dr. Furney came to the conference, and I am delighted to be writing the Series Foreword for such a wonderful accomplishment.

Dr. Furney's editor wrote me a note when she sent me the manuscript—it read, "You are going to love this book. It's terrific!" Indeed she was right—I do love it and it is terrific.

There are several reasons why it is such an insightful guide, including the fact that Furney is both a physician and a patient. Contracting MS (as the author prefers to call it) at the age of 34, just when she was considering having another child, was heartbreaking.

Dr. Furney begins with her own story and then leads us into the world of multiple sclerosis and offers sage advice based on current medical guidelines and personal experience. The combination is powerful and it is with pleasure that I encourage you to read this book.

Series Editor Julie Silver, M.D. Assistant Professor Harvard Medical School Department of Physical Medicine and Rehabilitation

PREFACE

"Multiple Sclerosis." What a terrible disease. This can't be right. Not me. Not now. I'm busy. I have a daughter, a husband, a job. How can I possibly go on?

I chose to write this book because I have never forgotten the flood of frightening thoughts and emotions that I experienced when I was diagnosed with multiple sclerosis (MS). I am hopeful that by sharing some of my experiences, your own path may be made a little easier as you either face a new diagnosis of MS or struggle with some of the challenges that arise during the first few years.

Being diagnosed with relapsing—remitting multiple sclerosis came as a tremendous shock to my whole sense of self. At age 34, I considered myself to be healthy and fit, and I was at a wonderful point in my family life and career. I had a bubbly, little fifteen-month-old daughter, and I was thinking about having another child. I had studied long and hard to finally be working as a physician of internal medicine. My husband and I were learning how to balance two careers while maintaining a strong sense of family. Then, one day, very unexpectedly, I began to feel lightheaded whenever I was standing. Next came the spinning sensation. Within a week, the diagnosis of multiple sclerosis caused the walls of my very happy life to come crashing down.

It has been seven years since I was "officially" diagnosed with MS and thirteen years since I had optic neuritis, often an early indicator of future MS. Fortunately, I still consider myself to be healthy and fit. I now have two daughters, a great part-time job, and a husband who continues to be a tremendous source of strength. I still exercise, help to coach my daughter's soccer team, and enjoy life to the fullest. And, yes, I regularly inject myself with medication because I do have MS. Yet, I can say with complete honesty that I do not feel like the MS has me. While some days are more challenging than others, I do not believe that my life has been dramatically altered because I live with MS. Most important, I have learned how to maintain hope for the future.

xii Preface

My path to reaching a point where I can make such statements included many difficult experiences. As I encountered various challenges along the way, I sometimes wished that I had a way to tell others with MS what I had learned in going through a particular situation. Eventually, I started writing down some of these thoughts, and I am glad to be sharing them with you now.

I am hopeful that my perspective as someone who is both a patient and a physician will allow me to have a better connection with you as a reader while still "getting the facts straight." Most often in writing this book, I share my thoughts as a person who has struggled with a decision or situation that arose because of my MS. As I do so, you will come to know that you are not alone in experiencing the spectrum of overwhelming emotions that may sometimes come with these challenges. Occasionally, I put on my "doctor's hat" and convey some pieces of advice that come from the in-depth reading I have done about multiple sclerosis because of my own illness. In sharing this dual patient-physician perspective, it is my hope that you will finish this book with some new ideas, attitudes, and understanding about living with MS.

One of the biggest challenges for me in writing this book was the realization that there will never be a "one size fits all" book for everyone living with MS. Multiple sclerosis is an illness that affects each individual in a slightly different way given its great variety of potential symptoms. In addition, we come from many different backgrounds, in many different colors, and speak many different languages. Therefore, no two people living with MS are likely to have identical symptoms or challenges. As you read, it may be helpful to keep in mind that we are all different. Yet, I am fairly certain that over time, there are many common emotions and situations that we encounter.

Since I do not want the main text of this book to be too technical or full of medical jargon, I am including an "appendix" that provides some of the more technical information that you may want to know about MS. It is important to realize that I am writing this book as someone living with the relapsing—remitting form of multiple sclerosis (RRMS). The appendix defines exactly what it means to have RRMS and also explains the other types of multiple sclerosis.

If you are newly diagnosed with multiple sclerosis, you may want to start by reading the first four chapters. The titles of the subsequent chapters are self-explanatory and you will know when you are ready or have the need to read them. For others who are further along in living with MS, you may choose to flip back and forth between chapters as various situations arise.

My overriding message to you is one of hope. As you can see from the chapter titles, there are clearly going to be some bumps in the road. In sharing my thoughts, I wish to make some of those bumps a little smoother. While it may take some time to come to terms with the diagnosis of MS, I do believe that you will come to a point where your outlook is positive and your life feels complete again.

ACKNOWLEDGMENTS

My greatest thanks goes to my husband, Scott. The only reason I found time to write this book is because he created that time for me by taking our children on countless expeditions to the park, pool, and other fun places. His support throughout the process was never-ending, even when my computer was seeing so much more of me than he was. As I have dealt with my MS over the years, he has been my sounding board and my source of strength.

Next, I thank my mother, whose proofreading of each chapter likely saved me from multiple rewrites for my publisher. I now understand and appreciate why she took so much time to teach me how to write when I was in elementary school.

I thank both my mother and my father for their gentle guidance and direction over the years. Their continuous support and faith in me has kept me going during the most challenging of times. My sister, Kathy, who lives a courageous life with cerebral palsy and a smile on her face, reminds me what life is all about.

My girls, who are now eight and five years old, had very little direct involvement in the creation of this book. Yet, they were always patient and understanding when I told them it would only be a few more months until mommy had her book written and could join them on the fun expeditions with daddy. In addition to my husband, they are the light of my life. Their giggles and hugs make life worth living.

I thank all of my close girlfriends who never seemed to tire of my talking about my book and my concerns about getting it done on time. I thank Susan Dorr Goold, M.D., who may not realize that she played a pivotal role in the first week of my diagnosis by being that person who *really* understood what I was going through. I thank Cicley Worrell Sullivan, whose example of optimism and courage showed me how much more I could be doing within the MS community.

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