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Parkinson's Disease FOR DUMMIES®

Michele Tagliati, MD
Gary N. Guten, MD, MA
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A Reference for the Rest of Us!®

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A diagnosis of Parkinson’s disease is a life-altering event. There is no one way to deal with it. Everyone has a unique set of circumstances, and every patient experiences Parkinson’s differently. That’s why one book on PD can never be all things to all people. Whether you are living with the disease or are a caregiver or friend to someone who is, you will come to rely on a wide variety of high-quality books, manuals, Web sites, resources and tools. You may be surprised by the voracity of your appetite for newer, better, and just plain more information about PD. And since Parkinson’s is — for now, at least — a disease that stays with you for life, your information needs may evolve and change over time.

This book represents something incredibly important: a place to start. We commend its emphasis on tenets that we at The Michael J. Fox Foundation strive to incorporate into our work: an action orientation, a problem-solving mentality, and the distillation of a great deal of complicated information into clear, logical next steps.

Most importantly, the Foundation shares with the authors of this book a commitment to keep patients front and center in every decision we make. As the largest funder of Parkinson’s research outside the federal government, we actively partner with scientists to innovate new funding mechanisms that can maximize the quality, quantity and pace of PD research. With a comprehensive view of the field and proactive management of the grants in our portfolio, we are ideally positioned to bridge the gap between basic research and the clinic. For years scientists have asserted that with sufficient research funding, a cure for Parkinson's is within reach. We are working urgently to prove them right.

I am continually inspired by the patients I meet who are endeavoring to live their lives beyond the potentially limiting effects of this disease, defining themselves by their achievements, not their struggle with PD. But no one who knows Parkinson's would suggest that a positive outlook is achievable all the time. Do everything you can to put the odds on your side: Find doctors you trust and can build relationships with; eat well and exercise as much as possible; appreciate and invest in your family and friendships; investigate ways to reduce stress and practice what works for you.

And know that work is continuing aggressively to make this disease, finally, a thing of the past.

Debi Brooks President and CEO, The Michael J. Fox Foundation for Parkinson's Research

About the Authors

Michele Tagliati, MD, is a movement disorders specialist with extensive experience in the diagnosis and treatment of Parkinson's disease. As Director of the Parkinson's Disease Center at Mount Sinai Medical Center in New York, he follows hundreds of patients at several stages of disease progression. He dedicates his professional life to caring for PD patients and developing research protocols that will ultimately improve their condition. In particular, Dr. Tagliati is a leader in the field of deep brain stimulation for PD and dystonia. He currently serves as teaching faculty at the annual courses given on DBS programming at the American Academy of Neurology and the International Movement Disorders Society. He has published over 40 peer-reviewed articles and 20 book chapters. A medical graduate and neurologist specialist from the University of Rome in Italy, he moved to New York in 1991 with a PD research scholarship. After completing a second neurology residency at Mount Sinai Medical Center, Dr. Tagliati served as a faculty member at Albert Einstein College of Medicine and then moved back to Mount Sinai to become Division Chief of Movement Disorders. He is currently Associate Professor of Neurology at Mount Sinai School of Medicine and a diplomate of the American Board of Psychiatry and Neurology.

Gary N. Guten, MD, MA, is qualified to contribute to this book for three reasons: He's a sports medicine orthopedic surgeon, author, and Parkinson's patient. As an orthopedic surgeon, he specializes in sports medicine, exercise, and nutrition. He was the founder of Sports Medicine and Orthopedic Center in Milwaukee, Wisconsin. The center now has eight doctors. As an author, he has published six books on sports medicine and 27 medical journal publications — 14 are on the Web site of the National Library of Medicine accessible at www.pubmed.com. As a Parkinson's patient, his insight and understanding of Parkinson's disease comes from the fact that he developed PD in 1995. He had to stop doing surgery — but continues to actively do office practice and consultations. Gary received his medical degree from the University of Wisconsin, and as a lifelong learner received a Master of Arts degree in 2005 in Bioethics from the Medical College of Wisconsin. His master's thesis subject was *Placebo Surgery* with a critical analysis of stem cell surgery for PD.

Jo Horne, MA. Many factors came together to lead Jo to this project. After receiving her master's degree in communications from the University of Cincinnati, she spent the early years of her career as a college lecturer. Later as she began an eight-year journey as the long-distance caregiver for her parents, she became aware of the need for a comprehensive guide for caregivers. Over the next several years she wrote three such guides, all published by AARP. At the same time, she left teaching to work with her husband as he and others pioneered the concept of adult day care in the state of Wisconsin. She was also a fellow of the Midwest Geriatric Education Center's initial class and was tapped to deliver the keynote address at the national meeting of the Association of University Professionals in Health Administration for her work in developing curriculum on professional/patient interactions in long-term care. Her work as a communications manager in the dual corporate worlds of long-term care insurance and later the pharmaceutical industry further prepared her to research and write on the effects of Parkinson’s on patients and their care partners. Finally when her sister was diagnosed with PD, Jo found herself up close and personal with the impact PD can have. Her unique combination of personal and professional experience has made her a popular speaker and workshop leader as well as a guest expert for national television and radio talk shows.

Dedication

Michele Tagliati, MD — In memory of my father, Silvano Tagliati, who suffered with great dignity from Parkinson's disease, and my beloved wife, Tracy, who greatly inspired my life as a man and a doctor.

Gary N. Guten, MD, MA — This book is dedicated to the lasting memory of my neurologist, Dr. Steven Park, who died in 2006 from a tragic accident. Not only was he a Parkinson's disease maven, but he was my medical mentor, respected colleague, and golfing buddy.

Jo Horne, MA — Every book is for Larry, whose belief in me has never wavered. This one is also especially for Patsy Horne DeBord — my sister and friend — whose fight with PD brought our family closer in spite of the years and miles separating us. It is also for my siblings, Betsy and Earle, and in-laws, Tom and Carole, who took on the demanding role of care partner for Patsy without hesitation and — learning on the job — performed it with love.

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Michele Tagliati, MD — I would like to thank Jo, whose enlightened spirit envisioned and inspired this book, and all my patients, who teach me a great deal about their disease every day. In addition, I would like to thank the Department of Neurology at Mount Sinai Medical Center and the Bachmann-Strauss Dystonia & Parkinson Foundation for their continuous support.

Gary N. Guten, MD, MA — One person stands out as being responsible for my insight, knowledge, and fight against Parkinson's disease. That person is my piano teacher — Rita Shur. She has taught me to play the piano (or write) — not with my fingers — but with my heart and my head.

Jo Horne, MA — Without the unique expertise and indefatigable dedication of Michele and Gary, this project would still be on the drawing board. I am indebted to both of them for their insights and humor as we made this journey. I am also deeply indebted to my agent Natasha Kern and everyone on the project team at Wiley Publishing. But as Willie Loman said in the Arthur Miller play *Death of a Salesman,* "Attention must (also) be paid" to the dozens of PWP, their care partners, and healthcare professionals who contributed to the work just by showing me what it means to live with PD. Finally I am profoundly indebted to those fearless and tireless

warriors at the foundations and organizations who daily wage the battle to find a cure. My deepest wish is that they make this book obsolete in a very short time.

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We’re proud of this book; please send us your comments through our Dummies online registration form located at www.dummies.com/register/.

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Contents

Introduction

If the very idea of a Parkinson's disease diagnosis scares the bejeebers out of you, take a deep breath and pay attention. Although Parkinson's is a chronic and progressive condition with no cure (yet), the strides made in just the last decade to control and manage symptoms are impressive and hopeful. Also the number of national organizations (not to mention big-name celebrities) that are placing the spotlight squarely on the need for a cure is unparalleled.

And we're here to help: An experienced neurologist and lecturer on the treatment of Parkinson's disease (PD); another physician — not a neurologist but rather one who has been living with his own PD (and finding new and innovative ways to maintain control over his life) for over a decade; and a writer of books on aging and giving care whose oldest sister has PD. Together we give you the facts you need, resources you can rely on, and tips on how best to structure your life so that — to paraphrase the popular slogan — you have PD, but it doesn't have you.

This book is your guide to understanding and living with PD. While you — the person with Parkinson's (PWP) are the primary audience — feel free to share *Parkinson's Disease For Dummies* with family, friends, and especially that person who will most likely make this journey with you — your care partner.

We — the doctor-athlete who's fought PD for over ten years, the writer who's seen dozens of people triumph over their PD, and the neurologist who's not in the business of giving up — wish you the strength to persevere, the will to keep fighting for a cure, and the physical and emotional stamina for a long, productive life.

About This Book

At first glance the idea of a *For Dummies* guide to Parkinson's disease may seem ludicrous or even downright insulting. But those of you who have used these guides understand that the dummies reference indicates a guide that presents its topic in simple, straightforward terms. Although PD doesn't have a cure, it can be well managed for years before a person faces its more challenging aspects. And that's what this guide is about — practical ways you can control and manage the symptoms of your Parkinson's so you can get on with your life!

Now, this is not some sugar-coated Pollyanna guide to living with PD. It's a realistic look at what you're facing. It provides solid information and resources to help you and your family come to terms with PD as a factor in all your lives. It offers proven techniques and tips to help you prepare for the future without projecting the worst. And most of all, it reminds you that living a full and satisfying life — in spite of PD — is definitely possible, even probable.

We designed each chapter of *Parkinson's Disease For Dummies* to be self- contained so that you don't have to read the book sequentially or read the first parts to understand any later chapters. You can dip in and out wherever you please and concentrate only on what you need. The table of contents and the index can help guide your search.

Conventions Used in This Book

The following conventions are used throughout the text to make the info consistent and easy to understand:

- All Web addresses appear in `mono font`.
- New terms appear in *italic* and are closely followed by an easy-to-understand definition. We also clearly define the terms in the handy glossary at the back of the book.
- **Bold** is used to highlight the action parts of numbered steps.
- This book has several sidebars (shaded in gray). These aren't essential to your understanding of PD or your use of this guide, but we hope you'll find them interesting and, in some cases, even inspiring.

This guide has a few special conventions that are widely accepted by Parkinson’s researchers and advocates as well as by people with PD and their families:

- Parkinson’s disease is often abbreviated *PD.*
- A person diagnosed and living with PD is often referred to as *PWP,* or person (or persons) with Parkinson’s.
- Because PWP are fully capable of making decisions and planning their care for many years following diagnosis, we refer to their primary caregivers as *care partners.* There may come a day when you need more hands-on care and assistance. Should that day come, that’s when your *care partner* takes on the additional role of *caregiver.*
- Although we hope your family and close friends will read many portions of this guide, some sections are do-not-miss for these folks. Several chapters have a section titled “A Word for the PD Care Partner” at the end. Be sure to share these sections with the person (or persons) most likely to be your support and eventual caregiver.

Foolish Assumptions

In putting together this guide to living with PD, the three of us have assumed the following about you:

- That you have (or suspect you have) PD yourself or are close to someone who does.