

Parkinson's Disease

FOR
DUMMIES®

**by Michele Tagliati, MD; Gary N. Guten, MD, MA;
and Jo Horne, MA**

Foreword by Deborah W. Brooks

President and CEO of The Michael J. Fox Foundation for Parkinson's Research



Wiley Publishing, Inc.

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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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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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Foreword

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

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.
- ✔ That you want reliable information about PD, and you’re looking for proven ways (techniques and resources) to treat and manage its symptoms.
- ✔ That you intend to take a proactive role in facing this challenge and not simply (blindly!) do everything the first healthcare provider you see tells you to do.
- ✔ That you’re open to lifestyle adjustments and complementary or alternative techniques that are proven to manage symptoms and prolong functions.
- ✔ That you realize PD is not just a physical condition that affects only you; it has elements that impact you — and everyone who cares about you — physically, mentally, and emotionally. You all need to be proactive in preparing for and meeting those challenges head-on.

How This Book Is Organized

All *For Dummies* books are divided into parts and chapters. The goal is for you to easily move from one part or chapter to another without having to read a gazillion pages of information that aren’t essential at the moment. Clever, right? The following sections describe each part.

Part I: Understanding PD

The chapters in this part explain what PD is and isn't. Chapter 1 gives an overview: statistics and background information plus the differences between primary PD and other conditions that can look like it. Chapter 2 gets into the potential causes — genetic and environmental — that researchers study to find new treatments and even a cure. You also find out who's at risk for getting PD. In Chapter 3 we take a closer look at the four major symptoms and signs that distinguish Parkinson's from related conditions. The chapter concludes with the stages of the disease and why these stages have no clear markers.

Part II: Making PD Part — But Not All — of Your Life

These chapters walk you through those initial steps following your suspicions of PD. We begin with guidance on getting an accurate diagnosis, finding a specialist, and understanding the tests and techniques that confirm your diagnosis. We explain how to connect with other health experts — therapists, counselors, and such — who will play a vital role in managing your PD. In addition, you need to focus on sharing the news with people around you. Chapter 7 gives you tips on how, when, and who to tell. The final chapter in this part addresses the special needs of people with young onset PD (before age 50).

Part III: Crafting a Treatment Plan Just for You

This is your guide to the current options for treating PD and managing symptoms over the long term. We look at prescription medicines, the possibility of surgery, and proven complementary or alternative therapies that are viable assets. The largest chapter is on diet and exercise, and that's intentional. We include a program of exercises specifically designed to enhance flexibility and build muscle strength. We also insist that you show this program to your physician and physical therapist before trying it on your own! Because PD is a neurological condition (affecting the brain), we include a separate chapter on depression and anxiety, which can be treatable symptoms of the condition itself. Wrapping up this part is a chapter on clinical trials. We discuss how to find such trials as well as the pros and cons of being a participant.

Part IV: Living Well with PD

Because living with PD for many years — even decades — is not only possible but also likely, this part discusses special areas of your life (people, work, and independence) that may need fine-tuning. We explain how people often react differently to a person who now has a chronic and progressive condition and how it's up to you to maintain normalcy with your family, friends, and co-workers. We also address PD and the workplace: the issues you face when you can work as well as the options you have when you can't work. Finally we cover ways to maintain independence and control over your life despite changes in your mobility and mental prowess.

Part V: Coping with Advanced PD

As with any progressive condition, you'll eventually delegate responsibilities and rely on other people to keep you mobile, mentally alert, and emotionally upbeat. This part of the book is as important for your primary care partner as it is for you, so both of you need to read it. We cover important decisions and planning processes that you should address early on, and we discuss the onset of later-stage symptoms that can be incapacitating. We also address the gradual shift of your partner's role from care partner to caregiver, based on ground rules the two of you make. Early discussions on housing, finances, and legal issues are also covered in this part.

Part VI: The Part of Tens

Every *For Dummies* book includes a section of lists, that is, key information that readers can use right away. In *Parkinson's Disease For Dummies*, those lists include ten ways to manage difficult feelings (anger, guilt, sadness, and such), ten ways you (the PWP) can care for your care partner, and — possibly the most important list — ten ways you and your care partner can become active in the fight for a cure.

Part VII: Appendixes

Appendix A contains a glossary of Parkinson's-related terms to use as reference. Appendix B summarizes the many PD resources we mention throughout this guide: organizations, care partner resources, support groups, and assistive devices for making life with PD easier.

Icons Used in This Book

To make this book easier to read and simpler to use, we include icons that help you find (and fathom) key information. Here's what they look like and highlight:



This icon flags essential information that cautions and protects you against potential pitfalls and problems. Do *not* skip over these paragraphs.



This icon signals essential information that's important enough to bear repeating. It's information you should keep in mind.



This icon identifies information that may save you time, offer a resource, or show you an easier way of doing some task or activity.

Where to Go from Here

Where you open this book — Chapter 1, Chapter 18, or somewhere in between — depends on where you are in your journey through Parkinson's. If you suspect PD is the cause behind some troubling symptoms, you may want to start with Chapter 4 for tips on the best way to get an accurate diagnosis. If you've already been diagnosed, then Part III, where we discuss treatment options, may be your first stop.

The point is that this is a *guide*, a roadmap to help you on the path to living with PD. We offer information and resources that you can trust — tools that help you adapt to life with PD without making it your whole life. In the long run, however, it's your resolve to face each day with renewed strength and energy that will see you through. And it's your example that will set the stage for those people who intend to partner with you in the fight.

Part I

Understanding PD

The 5th Wave

By Rich Tennant



“As explained, Parkinson’s disease is a depletion of dopamine in the brain. But before you fill up that space with a lot of negative thoughts, let’s discuss your treatment options.”

In this part . . .

You discover what Parkinson's disease is and how it differs from related forms of parkinsonism. We identify the current theories on causes for the onset of Parkinson's and the risk factors that may play a part for some people. Finally you get a good idea of what symptoms to watch for and what signs doctors look for to diagnose and stage this condition.

Chapter 1

Parkinson's Disease: The Big Picture

In This Chapter

- ▶ Setting the stage: What Parkinson's disease is — and isn't
 - ▶ Making a plan to establish your care
 - ▶ Maximizing your care options
 - ▶ Living (and loving) your life
 - ▶ Getting from here to there: Your present and future with PD
-

The National Center for Health Statistics (a division of the Centers for Disease Control) reports that approximately 1 percent of all Americans over the age of 65 receive a diagnosis of Parkinson's disease (PD). Sixty thousand new cases are diagnosed every year. But you didn't pick up this book because you're interested in mass numbers. You opened it because you're only interested in one number — yours or someone you love. You opened it because you've noticed some symptoms that made you think *Parkinson's*, or you just got a confirmed diagnosis and you're wondering what's next.

What's next is for you to go into action mode — understand the facts (rather than listen to the myths) about PD — what causes it, how it's treated, and, of huge importance to anyone diagnosed with PD, how to live with it. (Notice we said *live*, not just *exist*.) In this chapter, you find the big picture of the rest of the book and (more to the point) where to find the information that you need right now.

Defining Parkinson's — A Movement Disorder

Parkinson's disease is a disease in a group of conditions called *movement disorders* — disorders that result from a loss of the brain's control on voluntary movements. Dopamine (a neurotransmitter in the brain) relays signals from the substantia nigra to those brain regions (putamen, caudate, and globus pallidus — collectively named the *basal ganglia* — in the *striatum*) that control movement, balance, and coordination (see Figure 1-1). In the brain of people with Parkinson's (PWP), cells that produce this essential substance die earlier than normal.



Although a whole group of conditions are known as *parkinsonism*, the one that most people know is called *idiopathic PD*, a Greek word that means *arising spontaneously from an unknown cause*. As the term suggests, the jury is still out as to the underlying cause (though theories do exist).

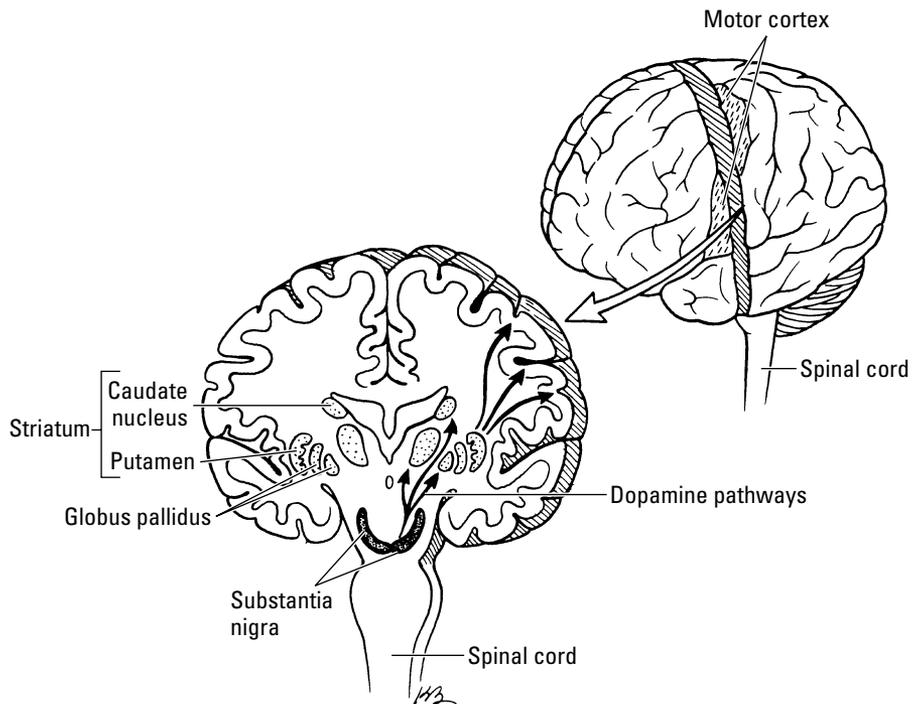


Figure 1-1:
The
dopamine
pathway.