LEARNING MADE EASY

2nd Edition

Parkinson's Disease for dummies

A Wiley Brand

Maintain your independence

Feel better with diet and exercise

Manage your symptoms

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Foreword by Deborah W. Brooks
CEO and Co-Founder of the Michael J. Fox Foundation for Parkinson's Research

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2nd Edition

by Michele Tagliati, MD
and Jo Horne, MA

FOREWORD BY **Deborah W. Brooks**
CEO and Co-Founder of The Michael J. Fox Foundation
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Parkinson’s Disease For Dummies®, 2nd Edition

Published by: **John Wiley & Sons, Inc.,** 111 River Street, Hoboken, NJ 07030-5774, `www.wiley.com`

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Published simultaneously in Canada

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Library of Congress Control Number: 2022940644

ISBN 978-1-119-89358-5 (pbk); ISBN 978-1-119-89359-2 (ePDF); ISBN 978-1-119-89360-8 (epub)

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Foreword

A diagnosis of Parkinson's disease (PD) is a life-altering event. There is no one way to deal with it. Everyone has a unique set of circumstances, and every person and family experiences Parkinson's differently. One book on PD could never be all things to all people. That remains as true today as when *Parkinson's Disease For Dummies* was first published.

Fortunately, little else in Parkinson's research and care has stayed the same. In fact, over the past decade our field has seen astonishing momentum. Parkinson's drug development today is overflowing with promise and possibility. Scientists are making real progress in understanding the disease. Tidal waves of data and insights are flowing directly into the R&D pipeline to accelerate better treatments on their path to pharmacy shelves.

Over the same period, the national and international community of people and families living with Parkinson's has become more energetic and engaged than ever before. It's a growing community, unfortunately, with some estimates suggesting that the number of people living with Parkinson's could double by 2040. But here's the good news: While no one joins this community by choice, once they are here, many find it to be a source of tremendous richness, comfort, and support.

The Michael J. Fox Foundation is privileged to work closely with people and families living with Parkinson's, and we partner with them on new ways to help you, too, live well with this disease. You may be surprised by the voracity of your appetite for up-to-date, trustworthy, and just plain *more* information about PD. And since Parkinson's — for now, at least — stays with you for life, your information needs will change over time. That's why we offer informational and support resources including events, guides, webinars, videos and podcasts, our Parkinson's Buddy Network to foster social connections, and much more.

But we know PD can still feel overwhelming on your best day. That's why *Parkinson's Disease For Dummies, 2nd Edition* continues to represent something incredibly important: a place to start. We commend its emphasis on tenets that Our Foundation also strives to embody: an action orientation, a problem-solving mentality, and the distillation of complicated information into clear, logical next steps. And most importantly, a commitment to keep those living with Parkinson's front and center in everything we do.

I am continually inspired by the people 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. So do everything you can to put the odds on your side. Build relationships with care providers you trust; participate in research studies that urgently need you; eat well and exercise as much as you can; invest in your family and friendships; practice stress reduction techniques that work for you.

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

Debi Brooks

CEO and Co-Founder, The Michael J. Fox Foundation for Parkinson's Research

Introduction

If the very idea of a Parkinson's disease (PD) diagnosis scares the bejeebers out of you, take a deep breath and pay attention. Although Parkinson's is a chronic and progressive condition that has 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 in the history of PD.

And we're here to help: An experienced movement disorders specialist, researcher, and lecturer on the treatment of Parkinson's disease (PD), and a writer of books on aging and caregiving who has years of experience as a care partner for members of her own family. Together, we give you the facts you need, resources you can rely on, and tips on how best to structure your life so that even though you may need to face living with PD, PD does not define you.

This book is your guide to understanding and living with PD. Although we assume that you — the person with Parkinson's (PWP) — are the primary audience, feel free to share *Parkinson's Disease For Dummies, 2nd Edition* with family, friends, and especially that person who will most likely make this journey with you — your care partner.

Neither of us — the writer who's followed dozens of people living with PD, and the doctor dedicated to those living with movement disorders such as PD — are in the business of giving up. We wish you the strength to persevere, the will to keep fighting for a cure, and the physical and emotional stamina to enjoy 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, you and your healthcare team can manage it well for years before you face its more challenging aspects. And that's what this guide is about — practical ways that you can control and manage the symptoms of your Parkinson's so that you can get on with your life.

Now, we won't insult you by offering some sugar-coated Pollyanna guide to living with PD. You deserve a realistic look at what you're facing. This guide 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 you can possibly — even probably — live a full and satisfying life, in spite of PD.

We designed each chapter of *Parkinson's Disease For Dummies, 2nd Edition* to be self-contained so that you don't have to read the book sequentially; don't worry about reading the first parts first if you want 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.

Foolish Assumptions

In putting together this guide to living with PD, we assumed the following about you:

- You have (or suspect you have) PD yourself or are close to someone who does.
- You want reliable information about PD, and you're looking for proven ways (techniques and resources) to treat and manage its symptoms.
- 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.
- You're open to lifestyle adjustments, and complementary or alternative techniques, proven to manage symptoms and prolong functions.
- You realize PD isn't 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 the challenges head-on.

Icons Used in This Book

REMEMBER

This icon signals essential information that's important enough to pull out of the general discussion and highlight.

TIP

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

WARNING

This icon flags essential information that cautions and protects you against potential pitfalls and problems. Don't skip over these paragraphs.

TECHNICAL STUFF

This icon marks the paragraphs that take a deeper look into the medical info surrounding Parkinson's disease. This icon doesn't appear often in this book, but where it does, you can feel free to skip that text if you don't want to take a deeper dive into the technical side of the disease.

Beyond the Book

In this book, we talk often about your journey of living with PD, and just like with any journey, you need more than a roadmap (or GPS). When you take an actual road trip, you likely pick up brochures or check out additional resources online to enrich your trip. To guide you on your PD journey, we offer a Cheat Sheet (go to `www.dummies.com` and search for "Parkinson's Disease For Dummies Cheat Sheet") — a kind of digest version of key tools for you to have on hand. We've also compiled a list of resources (see Appendix B) for you to explore — not all at the same time, but certainly little by little while your journey continues.

And one more thing: When you travel, connecting with others — locals or fellow travelers who have similar interests — always makes for a better trip. Your journey with PD is no different. Connecting with others through support groups (in-person or online), staying informed by signing up for newsletters and updates from groups such as the Michael J. Fox Foundation (`www.michaeljfox.org`), and perhaps becoming an active advocate for finding a cure can give your journey deeper meaning and purpose.

Where to Go from Here

Where you open this book — Chapter 1, Chapter 24, or somewhere in between — depends on where you are in your Parkinson's journey. 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 3, where we discuss treatment options, may be your first stop.

Use this book as 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 PD your whole life. In the long run, however, your resolve to face each day with renewed strength and energy will see you through. And your example will set the stage for those people who intend to partner with you in the fight.

1

Getting to Know PD

IN THIS PART . . .

Introduce yourself to Parkinson's disease (PD): what it is and what it isn't.

Weigh the risks of getting PD, and decipher the medical terminology surrounding the disease.

Decode your symptoms, now and in the future.

IN THIS CHAPTER

- Seeing Parkinson's disease for what it is — and what it isn't
- Making plans to establish and follow through on your care
- Getting from here to there: Your present and future with PD

Chapter 1

Parkinson's Disease: The Big Picture

The National Center for Health Statistics (a division of the Centers for Disease Control and Prevention) reports that approximately 1 percent of all Americans over the age of 65 receive a diagnosis of Parkinson's disease (PD). Doctors diagnose 60,000 new cases 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 — for you or someone you love. You opened it because maybe you 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 can 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 falls into a group of conditions called *movement disorders* (disorders that result from a loss of the brain's control on voluntary movements). The normal action of several neurotransmitters in the brain may be affected by PD. The best-known neurotransmitter is *dopamine*, which relays signals from the substantia nigra to certain brain regions that control movement, balance, and coordination. In the brain of people who have Parkinson's (PWP), cells that produce this essential substance (dopamine) die earlier than normal.

TECHNICAL STUFF

The brain regions that receive signals from the substantia nigra are the putamen, caudate, and globus pallidus — collectively named the *basal ganglia* — in the *striatum*; see Figure 1-1.

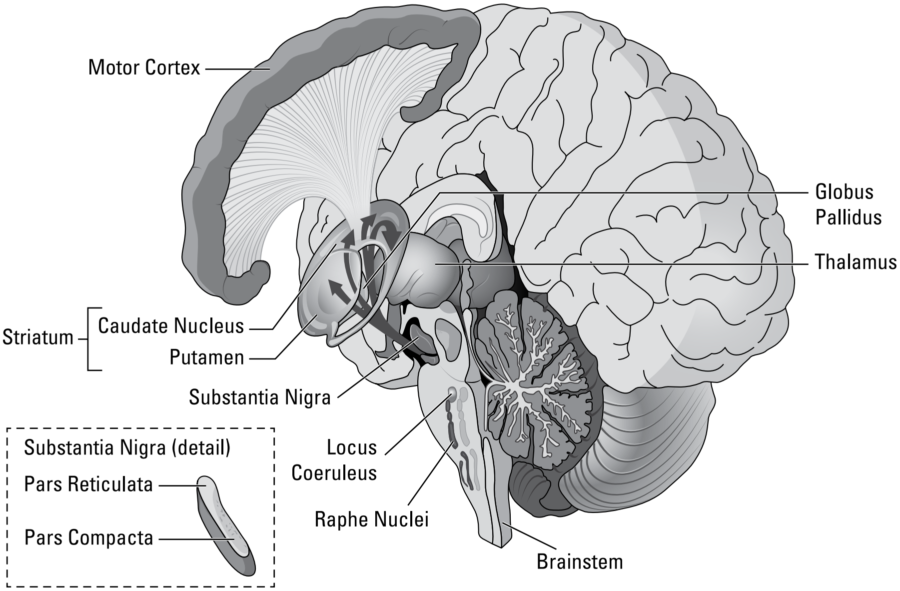

FIGURE 1-1: The dopamine pathway.

REMEMBER

Although a whole group of conditions can cause parkinsonism (as defined by rest tremor, bradykinesia or slowness of movement, rigidity or stiffness, and postural instability or propensity for falling), the exact cause of parkinsonism is unknown and therefore you will see the disease defined as idiopathic PD. *Idiopathic* is 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 (although theories do exist).

Navigating the unpredictable path

Go into a room filled with 50 people with Parkinson's (PWP), and they all vary when it comes to

- How they first suspected they had PD
- Signs of PD progression — from almost no progression to rapid onset of symptoms
- Attitudes and outlooks from the individuals dealing with their PD

REMEMBER

When you're diagnosed with PD, you set out on a unique journey — one where your outlook, lifestyle changes, and medical treatment can be key directional maneuvers along the way. In truth, this disease is one that you can live with, surrender to, or fight with everything you've got. The road veers and curves differently for each person. Some people may choose one path for managing symptoms, and some people choose another. Sometimes, the disease itself sets the course. The bottom line? No one can give you a clear roadmap. But you can count on one thing: Understanding the chronic and progressive nature of PD can take you a long way toward effectively managing your symptoms and living a full life.

Accepting the chronic progressive factors

Chronic and *progressive* can be scary words when you're talking about your health. But keep the words in perspective. Any number of chronic conditions occur with age — arthritis, high blood pressure, and high cholesterol, to name three. So, take a realistic look at the terms, accept them for what they are (and aren't), and move on.

Chronic: It's part of you now

In medical terms, illnesses are either *acute* (develop quickly and usually go away with treatment or time) or *chronic* (develop over time, may be managed with treatment, but have no cure at this time). In short, a chronic illness such as PD (or arthritis or high blood pressure) is now part of you — a fact that can help or hinder you as you work to build and maintain quality of life.

REMEMBER

If you refuse to accept that PD is a fact of life for you, then you're wasting precious time and energy in denial. Remember that most people face many challenges in life; if you can accept that PD is yours, then you're ahead of the game. Facing PD is no different than facing any situation that changes the way you think your life will turn out.

Progressive: It will get more challenging

Progressive, advancing, worsening — scary stuff. But to give you some good news: For millions of PWP, the progression takes years, even decades. Many PWP live relatively normal life spans following their diagnosis. However, two factors are essential for successfully containing PD's progressive effects: your attitude and your willingness to attend to lifestyle and medical therapy.

Throughout this book, we address both factors in multiple ways, but for now, remember

- **Your attitude:** Refusing to allow this diagnosis to color every part of your routine and life gives you a huge assist in coping with the management of new symptoms through the years.
- **Your willingness to take lifestyle changes seriously:** Also, get involved in the fight to find a cure (see Chapter 24 for how). Being proactive can make all the difference between you managing the disease or the disease managing you.

Recognizing symptoms that raise questions

First things first: Do you have PD? Although researchers may not yet have a clear idea of the cause(s) for PD (see Chapter 3), they have established that the neurological symptoms of idiopathic PD usually start only on one side of the body and include at least two of these four key symptoms:

- **Tremor at rest:** Trembling in the hands, arms, feet, legs, or chin when you aren't engaging that body part in activity
- **Rigidity:** Stiffness in the limbs and trunk, usually detected by the doctor and different from the joint stiffness typical of arthritis
- **Abnormal movements:** reduced dexterity and slowness of fine movements (*bradykinesia)*
- **Postural instability:** Impaired balance with tendency to fall or near fall

The first letters of the symptoms spell out the handy acronym *TRAP* to help you remember (like you need to be reminded!). The symptoms of PD can sometimes make you feel trapped inside your body. In this book, we work hard to show you a number of ways to fight back and maintain control of your life in spite of the TRAP.