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The Complete Guide for People With Parkinson's Disease and Their Loved Ones

Lianna Marie

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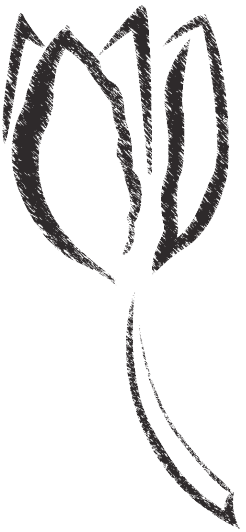

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For Mom.
Thirty years with Parkinson's and your faith
and determination never wavered.

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About the Author

A trained nurse, Lianna Marie served as her mother's caregiver and advocate for over 20 years through the many stages of Parkinson's disease. She founded AllAboutParkinsons.com, an online community that has connected and helped thousands of people with the disease, their families, and their caregivers.

The Complete Guide for People With Parkinson's Disease and Their Loved Ones is written for people recently diagnosed and their family members; *Everything You Need to Know About Caregiving for Parkinson's Disease* is a go-to resource for all caregivers of those suffering from Parkinson's. Both books share the goal of educating and helping everyday people with no specialized training, providing comprehensive information, practical tips, and guidance about how to deal with the emotional toll of the disease.

Marie speaks frequently to fellow caregivers, guardians, and nurse practitioners. Born and raised near Toronto, Marie now lives with her husband in Seattle. When not writing or speaking, she can be found in the swimming pool, training for her next competition. To learn more about Lianna Marie, her upcoming books, and her speaking schedule, visit www.liannamarie.com.

Also by Lianna Marie

Everything You Need to Know About Caregiving for Parkinson's Disease

The Parkinson's Path: Your Guide to Finding Hope, Happiness, and Meaning on Your Journey With Parkinson's

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A note from the author

If you enjoy this book or find it helpful, I would be very grateful if you would post a short review where you purchased it. Your support really does make a difference, and I personally read all the reviews.

Preface

Parkinson's has been a part of my life for the past 30 years. Throughout that time, I've been sharing my mom's story about her experiences with the disease, as well as my own as her caregiver and advocate.

Her name was Val and she had the disease for 22 years before she developed dementia as well. Along her journey with Parkinson's she learned a lot, both about how to live and cope with the disease, and about herself.

As her daughter and caregiver, I learned a lot too.

When she was diagnosed, there wasn't a lot of information available to help us understand what it meant to have Parkinson's. We found a couple of medical books, but it was hard to find anything written by someone who'd actually lived with the disease. So instead, we learned about Parkinson's by living with Parkinson's.

In 2005 when I wrote *Everything You Need to Know About Parkinson's Disease*, Mom had been living with Parkinson's for 15 years. She told me back then she wished there were more information available to help her understand and deal with her disease as it was progressing, and written in a way that she could understand. At that point no one had told us how powerful music could be in helping her mobility, or that there are reasons *not* to join a support group (there are definitely pros to joining one, but there are also cons), or that sometimes symptoms could disappear just by being really happy. We discovered these and many other useful nuggets on our own.

Together we came up with the idea of asking people with Parkinson's, as well as their families, friends, and caregivers, the most important questions they had about the disease. We received a lot of questions, both general and specific, and then answered them in the book.

Now, 20 years later, there's so much available to us online. You can pretty much Google anything you want and be inundated

with information. The problem is, how do you know where to go? With so many websites out there (not to mention the ones whose main goal is to sell you some kind of drug therapy), it can be overwhelming.

In *The Complete Guide*, I've answered new questions and updated old answers and tried to keep the information as succinct as possible. Each chapter begins with a tip or observation from one of my readers—one of the many I've received over the years. Whether you have Parkinson's or you know or care for someone who does, I hope this book will help you get the most important information in a way that you can understand.

Though Mom has now passed, my reason for writing the book remains the same: I want everyone who is affected by this disease to be as informed as possible so they can continue to lead happy, hopeful, and meaningful lives.

—Lianna

Words You Need to Know

Acetylcholine: a chemical found in nerve cells that transmits electrical impulses in the brain, the peripheral nerves, the heart, the bladder, the gut, and the muscles

Antioxidant: an enzyme or other organic substance, such as vitamin E or beta-carotene, that is capable of counteracting the damaging effects of oxidation to the cells in the body

Bradykinesia: slowness of movement

Dopamine: a chemical substance (neurotransmitter) found in the brain that sends impulses from one nerve cell to another and helps to regulate movement, balance, attention, learning, and emotional responses; the substance that is lost with Parkinson's

Dopamine agonists: drugs that imitate the effects of dopamine

Dyskinesia: an involuntary movement that can accompany peak doses of levodopa; the most common and disruptive side effect of Parkinson's medications

Dystonia: sustained muscle contractions or cramps that some people with Parkinson's experience

Excessive daytime sleepiness (EDS): a condition that causes people with Parkinson's to fall asleep or doze frequently during normal waking hours

Freezing: when people with advanced Parkinson's have a temporary, involuntary inability to move; sometimes referred to as "FOG," or "freezing of gait"

Glutathione: an antioxidant in the brain that is responsible for cell detoxification and is deficient in people with Parkinson's

Levodopa: the most effective antiparkinsonian drug; levodopa is changed into dopamine in the brain and is usually combined with the drug carbidopa and marketed as Sinemet

Neurologist: a specialist in the diagnosis and treatment of disorders of the nervous system (*Note:* In this book I often use the word *doctor* instead of *neurologist*)

On/off time: the cycle that people with Parkinson's go through in relation to their dose of levodopa medication; "on" refers to the time when the medication is working to control symptoms, and "off" refers to when it has worn off and symptoms are poorly controlled; off times are more common as the disease progresses

Parkinsonism: the umbrella term given to a group of neurological disorders that feature Parkinson's movement symptoms such as bradykinesia, tremor, stiffness of muscles, and gait and balance problems

PD: short form for Parkinson's disease

Pill rolling tremor: a typical Parkinson's tremor; it looks like the person is rolling a pill between the thumb and forefinger

PWP: a person with Parkinson's disease

Restless legs syndrome (RLS): an irresistible desire to move the legs and a common cause of sleeplessness in Parkinson's

Tremor: involuntary shaking of the hands, arms, legs, jaw, or tongue

Young-onset Parkinson's disease (YOPD): the diagnosis given to someone aged 21 to 50 years; also known as early onset Parkinson's disease

PART 1

Parkinson's Explained

1. What Is Parkinson's?

> "Be your own Parkinson's expert. Read as much about it as you can. Look up the research (including the meaning of the obscure words!). Many GPs are not able to keep up with the latest research and developments in Parkinson's. They don't have the time—but often we do." —JOHN G., PWP

To put it simply, Parkinson's is a disease that affects the functioning of a small part of the brain. It is named after an English doctor and writer named James Parkinson who first described the disease in *An Essay on the Shaking Palsy* back in 1817.

What happens in a person with Parkinson's is that certain nerve cells in the small part of the brain called the substantia nigra start to degenerate. And when they do, a chemical in the brain called dopamine is lost.

Dopamine helps transmit signals, or messages, from the brain to different parts of the body. When dopamine levels are reduced and the brain can't send signals as well, this causes problems with body movement. The resulting motor (movement) symptoms can include tremor, stiffness in the arms and legs, slowness of movement, and gait and balance problems. There are also resulting nonmotor (nonmovement) symptoms, which can include depression, anxiety, apathy, cognitive impairment (including dementia, most often in later stages), abnormal blood pressure swings, bladder dysfunction, sleep behavior disorders, constipation, and loss of sense of smell.

Studies have found that by the time symptoms appear, most people have lost anywhere from 40 to 60 percent of their dopamine-producing cells in the substantia nigra.[1]

The bad news about Parkinson's is that it is a long-lasting disease that gets worse over time. The good news is that because the disease progresses slowly, it usually takes years before there is a serious impact on a person's quality of life.

Below are some quick stats on who Parkinson's affects.

- Though estimates vary (it's difficult to get an exact number due to challenges in data reporting in some countries), currently the Parkinson's Foundation lists the number of people living with Parkinson's disease worldwide at over 10 million.[2]
- From 1990 to 2015, the number of people with PD doubled worldwide to over 6 million. Driven principally by aging, this number is project to double again to over 12 million by 2014.[3]
- Almost 1 million Americans live with PD (this is more than the combined number of people diagnosed with multiple sclerosis, muscular dystrophy, and Lou Gehrig's disease).[4]
- Over 100,000 Canadians, over 100,000 Australians, and approximately 150,000 people in the UK are living with the disease.[5]
- Aging is the greatest risk factor for PD, and 60 is the average age of diagnosis.[6]
- 10 to 20 percent of people with PD develop it before the age of 50.[7]
- Men are more likely than women to develop PD.[8]
- Some studies have shown the disease to affect Caucasians more than African Americans or Asians,[9] although the reasons for this may be more complex than just biological differences. More research needs to be done before we understand how ethnicity affects the likelihood of developing PD.

From 1990 to 2015, the number of people with PD doubled worldwide to over 6 million. Driven principally by aging, this number is projected to double again to over 12 million by 2040.

2. Stages of Parkinson's

"If you met me, you would not know that I suffer from Parkinson's—that's the truth." —BRIAN D., PWP

In the mid-1960s Dr. Melvin Yahr and Dr. Margaret Hoehn of the Columbia University Department of Neurology developed a scale still in use today (the Hoehn and Yahr Scale) that rates Parkinson's motor symptoms on a scale of 1 (early stage) to 5 (advanced stage). The symptoms may be mild or severe and may occur frequently or not as often. Also, the time spent at each stage of the disease varies, and the skipping of stages, from Stage 1 to Stage 3, for example, is not uncommon.

Stage 1: The main symptoms—tremor, muscle stiffness, slowness of movement, and problems with posture—occur only on one side of the body.

Stage 2: At this stage symptoms occur on both sides of the body, and minor problems with swallowing and talking, and what is known as facial masking (loss of facial expression), may be noticed.

Stage 3: Stage 1 and 2 symptoms may have worsened, and problems with balance are noticed for the first time. At this stage the person with PD is still independent.

Stage 4: The person with PD is now more disabled and needs help with some or all activities of daily living.

Stage 5: At this final stage the person with PD is confined to a wheelchair or bed and needs around-the-clock care for all activities. The person may experience hallucinations and delusions.

Another rating scale, the Unified Parkinson's Disease Rating Scale (UPDRS), is often used with the Hoehn and Yahr scale. The UPDRS combines elements of several scales, resulting in a much

more in-depth scale than the Hoehn and Yahr. For example, the UPDRS includes an evaluation of mood, behavior, cognitive abilities, ability to carry out daily activities (the Schwab and England ADL [activities of daily living] Scale is used), treatment complications, and movement symptoms. Points are assigned in each category based on the patient's responses and examination. The UPDRS allows neurologists to document a person's initial Parkinson's diagnosis examination and compare it with follow-up visits. The maximum total score is 199, which represents total disability, whereas a 0 score represents no disability.

Motor scales are important, but scales that evaluate the nonmotor symptoms are equally as valuable. Used in combination, they can give a balanced picture of how a person is being affected by PD. New nonmotor scales are being developed, including ones that assess sense of smell.

3. Parkinson's Disease vs. Parkinsonism

> "Don't give up. Do what you can as long as you can. On top of 10 years with Parkinson's, I had a stroke. Now, at age 91, unable to stand or take a step, I get around in an electric wheelchair in a life-care community and still do as much for myself as I can. Focus on what you have left, not on what you have lost."
>
> —VERNA W., PWP

If you've been diagnosed with Parkinson's disease, your neurologist or movement disorder specialist may have referred to it as "idiopathic." This means the cause of the disease is unknown. Approximately 10 percent of people diagnosed with Parkinson's have a genetic form of the disease.[10]

If instead you have Parkinson's-like symptoms but your doctor knows or suspects a cause for them, or if you don't respond to the usual PD therapy, your doctor may have told you that you have a type of *parkinsonism*.

There are many types of parkinsonism, and it is important to note that it's often difficult to distinguish between them and idiopathic PD, especially when the condition is mild. Also, many people don't show all the signs of any one type of parkinsonism. If this occurs, your doctor may diagnose you as simply having parkinsonism.

Below are more detailed descriptions of idiopathic PD and parkinsonism.

IDIOPATHIC PARKINSON'S DISEASE

Idiopathic Parkinson's disease is the name for the most common form of the disease. You may have also heard it called classic Parkinson's.

People with idiopathic Parkinson's are diagnosed when they have at least two of the four cardinal motor symptoms (bradykinesia plus one of three: rigidity, resting tremor, or balance problems); when there is no history of brain injury or other illness affecting the brain, or any other known cause of the symptoms; and when there is a good response to levodopa, the main medicine for Parkinson's. In idiopathic Parkinson's, the progression tends to be slow and varies from person to person.

PARKINSONISM

Parkinsonism is the umbrella term given to a group of neurological disorders that feature Parkinson's movement symptoms such as bradykinesia, tremor, stiffness of muscles, and gait and balance problems.

The types of parkinsonism can be categorized as either neurodegenerative (also known as atypical parkinsonism, previously Parkinson's plus) or secondary parkinsonism.

Neurodegenerative parkinsonism

Parkinson's symptoms may appear in patients with other neurological disorders, such as the following.

- Dementia with Lewy bodies (DLB)
- Multiple system atrophy (MSA)
- Progressive supernuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- Parkinsonism–Dementia–Amyotrophic Lateral Sclerosis Complex (PD–ALS)

You can read more about these types of parkinsonisms in chapter 6.

Secondary parkinsonism

Parkinson's symptoms may be caused by certain medicines or another illness. These types of parkinsonism include the following.

drug-induced parkinsonism (dip)

This form of parkinsonism is reversible and occurs when medications cause movement symptoms such as tremor, stiffness, and slowness. The medications often at fault are dopamine blockers, such as those used to treat schizophrenia and other psychiatric illnesses.[11]

A drug used to treat nausea and indigestion (metoclopramide), as well as one used to treat dizziness and nausea (prochlorperazine), may also produce Parkinson's symptoms.[12] Stopping or lowering the dosage of these medications causes the symptoms to go away.

vascular (arteriosclerotic) parkinsonism

This type of parkinsonism is sometimes known as pseudoparkinsonism. It results from damage to blood vessels due to multiple small strokes. You probably won't see tremors in this type of parkinsonism, but you most likely will see prominent gait and balance problems and cognitive impairment (loss of mental skills and abilities).

Drugs used to treat PD don't really help people with this type of parkinsonism. Treatment of vascular parkinsonism focuses on trying to lower the chances of having additional strokes in the future by attempting to control risk factors.

toxin-induced parkinsonism

Some toxins, like manganese dust, carbon disulfide, and carbon monoxide, can also cause parkinsonism. A chemical known as MPTP (methyl-phenyl-tetrahydropyridine) causes a permanent form of parkinsonism that closely resembles PD.

Researchers discovered this reaction in the 1980s when heroin addicts in California who had taken an illicit street drug contaminated with MPTP started to develop severe parkinsonism.[13]

MPTP-induced parkinsonism is very rapid in its onset (as quick as a few days to full symptoms), whereas idiopathic PD has a slow progression and may take years to become evident.

PARKINSONISM DUE TO OTHER CAUSES

Parkinsonism symptoms may also appear as a result of brain injury, brain damage caused by anesthesia drugs (such as during surgery), meningitis, narcotics overdoses, mercury poisoning, and HIV/AIDS.

4. What Causes Parkinson's?

> "My journey thus far fighting this disease has been a lot of education, a lot of reading, and teaching myself how to deal with it. As you know, it affects everyone differently. . . . I also believe that we must keep it together as much as possible. We must PUSH ourselves." —JUDY J., PWP

As of this writing, we still don't know exactly what causes Parkinson's. Researchers often theorize that PD is a response to a combination of environmental triggers and genetic factors,[14] but no single theory has yet been proven.

Following are several possible causes of PD that researchers are looking into.

Genetics

Having had a mom with PD means I have been keenly interested in genetics. Does having a close relative with Parkinson's mean that I will get it too? And if I have kids, will they be at risk as well?

Fortunately for me, the chances are small. While certain genetic variations can cause an inherited form of PD, direct genetic causation accounts for only about 10 percent of Parkinson's cases thus far. The primary culprit is a gene called *LRRK2* (leucine-rich repeat kinase 2), and it is the greatest known genetic contributor to PD (accounting for 1 to 2 percent of all cases).[15]

Researchers are also studying several other genes and their mutations that may contribute to the disease.[16] These include the *SNCA* (synuclein alpha) gene; the *GBA* (glucocerebrosidase beta) gene, more common in people of Ashkenazi Jewish descent; and the *PRKN* (parkin) gene, which commonly contributes to young-onset Parkinson's disease (YOPD).

Gut health

You may have heard that digestive issues like constipation are common in people with Parkinson's; you might experience these yourself and wonder what the heck is going on. A growing body of research now suggests that Parkinson's disease may be directly related to the health of your gut.

Some of these studies suggest that PD actually *begins* in the gut, and then navigates to the brain to cause the hallmark Parkinson's symptoms, like tremors. However, this is just a hypothesis and far from a proven fact. Symptoms may result from certain proteins affecting the vagus nerve that cause nerve cell death if they hit the brain, or from consuming substances that set off inflammatory reactions or alter the composition of healthy bacteria that reside along the gastrointestinal tract.

Whether from a poor diet, a microbiome imbalance, or preexisting condition, if your body isn't able to fight off the toxins and bacteria that enter your GI system like it used to, then the bad stuff passes right through your gut wall like it's an open door (when it should be locked to all but the best of guests). After hitting the bloodstream, these bad toxins wreak havoc on your body. This poor gut health leads to, among other things, inflammation, which is also linked to the development and progression of neurological disorders like PD and Alzheimer's.

So, while there is no exact answer for whether PD begins in the gut or simply reacts to changes within it, it is clear that your GI health and your brain health are connected and should be treated with equal respect. See chapter 46 for a breakdown of the best dietary practices for people with PD.

Pesticides

Studies have shown that being exposed to pesticides may increase a person's risk for developing Parkinson's disease. Research from the National Institutes of Health in 2011[17] showed a link between the use of two pesticides, rotenone and paraquat, and PD. Exposure to either of these pesticides increases the chances of developing the

disease by a significant amount. The study revealed that people who had been exposed developed PD 2.5 times more often than those who had not been exposed. Farmworkers who regularly used these pesticides were most at risk. Due to their toxicity, negative effects on the brain, and strong links to Parkinson's, the usage of both of these pesticides is now largely restricted.

Head trauma

Researchers have been looking into potential links between head trauma, or traumatic brain injury (TBI), and PD for some time. TBI occurs when there is a disruption in the normal function of the brain caused by a bump, blow, or jolt to the head. Many people think of Muhammad Ali and his diagnosis of Parkinson's being an obvious case for this association. A review of several published studies[18] found an association between head trauma and an increased risk of developing PD, and those with a history of head trauma resulting in concussions had an even higher risk.

It is important to note that even though head trauma and TBI are associated with an increased risk of developing PD, researchers warn that this does not mean that head injuries *cause* the disease. One theory is that TBI is one of many potential environmental factors that may interact with genetics to bring upon a diagnosis of Parkinson's. Additional research needs to be done to more definitively deem this to be true.

Exposure to metals

It is possible that occupational exposure to various metals (e.g., copper, lead, and manganese) can be related to the development of Parkinson's. Researchers have been looking into this, but it's difficult to measure long-term exposure to metals, and the results of studies measuring PD risk and specific metals have been inconsistent.

For example, people need small amounts of the element manganese to stay healthy. When the dosage gets too high, though, it becomes poisonous. High-dose manganese exposure is known to cause a form of parkinsonism called manganism, which is characterized

by feelings of weakness and lack of energy, tremors, a masklike face, and psychological disturbances. Researchers have focused on welders and miners who may have been exposed to high levels of manganese,[19] but so far we do not know if this or other types of metals can actually cause Parkinson's.

Oxidative stress

Free radicals are atoms in the body that have unpaired electrons. An atom with unpaired electrons will do whatever it can to get those electrons paired off, meaning it is quick to react with things it shouldn't. The instability of free radicals makes them dangerous: they can damage good cells and create abnormal ones. Fortunately, most of the time the body naturally produces antioxidants to counteract free radicals and detoxify any harmful effects.

Producing a small number of free radicals is normal and manageable. The problem arises when there are too many and the body's antioxidants can't keep up. The excess free radicals will do more damage than can be undone. This is called oxidative stress. It is possible that environmental toxins (e.g., pollution, cigarette smoke) may contribute to abnormal free radical formation, thus putting the body into oxidative stress and potentially leading to PD.

Postencephalitic Parkinsonism (PEP)

Around the time of World War I there was a viral disease called encephalitis lethargica that attacked nearly five million people throughout the world, then suddenly disappeared in the 1920s.

PEP became more widely known through neurologist Oliver Sacks's personal account of his work with PEP patients in a New York hospital in the late 1960s. Titled *Awakenings*, Sacks's book explores his use of the then-experimental drug levodopa to temporarily awaken patients trapped in a statue-like state. Today the incidence of PEP has dropped to nearly zero.