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

Lianna Marie

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Everything You Need
to Know About

CAREGIVING

for Parkinson's Disease

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Lianna Marie

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*For Muriel,
one of the all-time great caregivers*

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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

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

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

Fighting Parkinson's: 15 Vital Exercises to Help You Fight the Progression of Parkinson's

How to Parkinson's Proof Your Home: The Essential Guide to Making Your Home Safer for Living With Parkinson's

Find these books and free resources at AllAboutParkinsons.com.

ABOUT THE AUTHOR

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

My mom lived with Parkinson's for 30 years. She spent the last eight years of her life battling dementia as well, which made for an extra challenging time for those of us who loved and cared for her. If you've experienced dementia with a loved one, I know you understand.

Even though Mom succumbed to dementia, I think most would say it's remarkable that she survived three decades with Parkinson's, given that the average amount time people with this disease have from diagnosis to death is 16 years. I believe it was her faith and determination, as well as the caregivers she had over the years, that made the most significant difference.

Mom was fortunate enough to have a team of people around her that helped make life easier as her illness progressed. I was one of those team members, and my role was hands-on for most of that time, either in her home or in nursing homes in the late stages of her disease. For a few years I cared for Mom long distance and experienced how hard that can be, so I certainly relate to folks who've had to do that for their loved one.

When Mom was in the early stages of PD, she only needed help with simple tasks like getting out of a chair or car seat now and then. Over time, Mom's needs increased and tasks like helping her walk to the bathroom when her wheels (aka legs) were shut down, delivering medications to her at the scheduled times, and taking on household jobs like cooking and cleaning were just a few of the things that I, as well as her other caregivers, took on.

One of Mom's caregivers through the mid-stages of her disease was her husband, Dave. They married in the 10th year of Mom's illness, and he vowed to take care of her "in sickness and in health." Dave took on many of the tasks Mom needed doing, all while trying to maintain a stress-free environment for her so as to minimize her symptoms—an assignment most people would find challenging.

As the years passed, the physical stress and emotional demands of caregiving became too much for Dave, so both he and my mom sought external help. This help took many forms, including care workers who helped them in their home, support groups for both of them, a short-term respite from a care facility, and caregiving from family members like myself.

Unfortunately, throughout his many years of caring for Mom, Dave neglected to take care of himself. He developed diabetes as well as skin and colon cancer. Despite his illnesses, Dave was a loyal and loving caregiver. He visited Mom in the nursing home and took her on outings whenever he was able. He even volunteered and helped raise funds for his local Parkinson's foundation. Sadly, his illnesses became too much for him, and Dave passed away.

I know our story is not unique. Having read hundreds of stories from fellow Parkinson's caregivers, I found that many are doing their utmost for their loved ones with Parkinson's but are finding it overwhelming and sometimes detrimental to their health.

As a caregiver and advocate for my mom, I embarked upon a mission to help her receive the best quality and quantity of care possible. After seeing the toll that caregiving took on Dave and, conversely, what his and my family's efforts did to help improve Mom's quality of life, I feel compelled to help other caregivers care for themselves while caring for their loved one.

I hope this book can be a new chapter in your caregiving journey—one in which you find encouragement and support, as well as practical tips and guidance, to help you navigate the various challenges you may face.

I will finish here with a quote from an interview Mom gave around the 12th year of her journey with Parkinson's. She was speaking about what enabled her to keep going day after day, but I think it applies to us caregivers as well: "Each day we must remind ourselves why we do what we do. We must find meaning in our lives outside of caregiving and focus on the joys and fulfillment we can gain from caring for our loved one."

—*Lianna*

Words You Need to Know

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"

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

Caregiving Essentials



1. Who Cares?

“I don’t consider caring for my Mom a ‘job.’ Though some days are emotionally draining, it’s the least I could do for the person who gave me the wonderful life I’ve lived. I wouldn’t trade the time I’ve spent with her for the world.”

—ANONYMOUS, PARKINSON’S CAREGIVER

When you hear the word caregiver, what you think of will most likely depend on whether you’ve ever been one. Google may tell you it’s merely a person who gives help and protection to someone (such as a child, an older person, or someone who is sick), but what they don’t expand on is what that help might look like, practically speaking.

Those of us who have been a caregiver for someone with Parkinson’s know you can’t sum up our role in one short sentence. Our responsibilities may include helping our loved one with daily tasks such as preparing meals, shopping, housekeeping, and laundry; keeping track of medication schedules and prescriptions; assisting with or being in charge of finances; assisting with bathing, grooming, dressing, toileting, and exercise; taking them to appointments; helping them get in and out of a wheelchair, car, or shower; helping them walk through doorways or cramped spaces; or being their companion, cheerleader, and emotional supporter.

In this book I will be discussing issues specific to those caring for someone with Parkinson’s disease and topics that are relevant to caregivers of any kind. Yes, you must understand that regardless of whom you are caring for, many of the problems you will face apply to ALL caregivers. In other words, you are not alone.

You may be surprised to learn just how many caregivers there are in this world. Estimates indicate there are almost 44 million people providing care for a family member or loved one in the United States, 7.8 million in Canada, 6.5 million in the U.K., and

2.7 million in Australia . . . And those are just the countries on which I could find statistics!¹

Here are some quick stats on caregiving in the U.S.²

- Nearly 44 million adults are providing personal assistance for family members with disabilities or other care needs.
- 60 percent of caregivers are female.
- The average age of caregivers is 49.
- The typical caregiver has been helping a parent or spouse for four years.
- More than 15 million caregivers provide care for someone with dementia.
- A third of family caregivers say they do it alone, receiving no help from anyone.
- Over one-quarter of caregivers are “sandwiched” between caregiving and raising children.
- 6 in 10 caregivers care for an adult with a long-term physical condition.
- 6 in 10 caregivers are employed.

Caregiving types

There are many types of caregivers; some live in the same house as their loved one, whereas others live miles and miles away. Some are spouses, while others are sons or daughters. Some may even care for a parent while still caring for their own children. When I was my mom’s caregiver, I did so both in a live-in situation and while living far away from her.

The following are the main types of caregivers to whom most organizations refer. Note that you may fall into more than one of these categories.

The crisis caregiver: This term applies if your loved one or family member does fine on his or her own until there’s an emergency—that’s when you step in.

1. Who Cares?

The working caregiver: You are taking on a caregiving role (be it physical and/or financial) in addition to holding down a part-time or full-time job.

The sandwich generation caregiver: This term was coined to describe those caregivers who take care of not only their children but their elderly parents too. They are “sandwiched” between two generations.

The spousal caregiver: When a life partner becomes ill, a caregiver must deal with many challenging and sometimes heart-wrenching issues, including adjusting to one’s partner becoming the patient, as well as intimacy issues.

The long-distance caregiver: If you live in a different city, state/province, or country than your loved one, you are a long-distance caregiver. Even though they live far away, long-distance caregivers can be responsible for the financial, medical, and personal needs of their loved ones and help them by telephone.

Though the term may sound a bit funny, the sandwich generation caregiver has become so prevalent in our society that both Merriam-Webster and Oxford University Press have added “sandwich generation” to their dictionaries.

