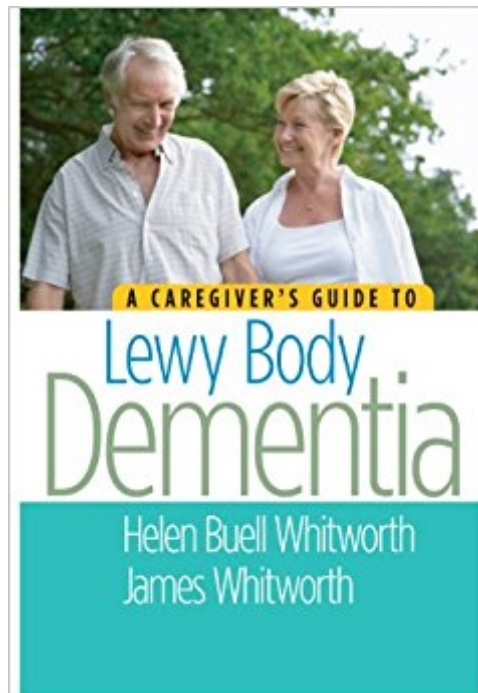




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A Caregiver's Guide To Lewy Body Dementia



Synopsis

"Received a 2012 Caregiver Friendly Award from Today's Caregiver Magazine Although Lewy Body Dementia is the second leading cause of degenerative dementia in the elderly, it is not well known or understood and is often confused with Alzheimer's Disease or Parkinson's. The Caregiver's Guide to Lewy Body Dementia is the first book to present a thorough picture of what Lewy Body Dementia really is. A Caregiver's Guide to Lewy Body Dementia is written in everyday language and filled with personal examples that connect to the readers' own experiences. It includes quick fact and caregiving tips for easy reference, a comprehensive resource guide, and a glossary of terms and acronyms. This is the ideal resource for caregivers, family members, and friends of individuals seeking to understand Lewy Body Dementia."

Book Information

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Customer Reviews

"It is a valuable resource for caregivers, which include spouses and children as well as nurses and nurses' aides caring for people with dementia. Family doctors and neurologists also will benefit, as it uncovers a lot of questions that they should address during visits with these patients. This is a great resource for information about dealing with LBD, although it is not a substitute for physician advice on specific care issues, especially medications."-Doody's "Lewy body dementia is a common cause of memory, motor, emotional and behavioral disturbance in the older adult, yet many people (including physicians) are unfamiliar with the signs, symptoms, and course of the illness. This lack of information can have devastating consequences on the patient, their family, and by extension their healthcare providers. Jim and Helen Whitworth have done an outstanding job not only of collecting a

comprehensive compendium on all aspects of LBD, but they also have provided a personal touch with a moving compilation of anecdotes, stories, and quotes. I commend them for their efforts and will most certainly recommend this book as required reading for all my LBD patients and their families."-James E. Galvin, MD, MPH, Professor of Neurology and Psychiatry, Director of Clinical Operations, Center of Excellence on Brain Aging. Director, Pearl Barlow Center for Memory Evaluation and Treatment, New York University Langone School of Medicine "This book will make a difference in the lives of caregivers who help to manage the LBD patient with the ever constant fluctuations and the many issues that come with the disease."-Irene Selak, a 5-year volunteer with the Lewy Body Dementia Association (Natalya V. Shneyder Doody's 20110204) --Lewy Body Dementia Association

"Jim Whitworth's first wife was diagnosed with Lewy Body Dementia. Propelled by the lack of information on the disease that led to his wife's plunging into severe dementia and subsequent demise in 2003, he co-founded the now nationally known Lewy Body Dementia Association (<http://lbda.org>). ||In 2005, he married Helen Whitworth, a retired nurse with training and writing experience. Together they author The Thistle, the LBDA newsletter. They also teamed up to present classes on LBD to dementia care staff, volunteers, caregivers and the general public Riding the Roller Coaster with Lewy evolved from these classes. ||Lewy Body Dementia is the second leading cause of degenerative dementia in the elderly. If so many people have LBD, then one might think that it would be fairly well known. But it is not. It is only now that LBD has some acceptance as a ""real"" dementia and a stand-alone disease. Six years after founding their organization, the Whitworths still find people confusing LBD with Alzheimer's disease (AD). One of the goals of this book is to shed some light on that confusion.|"

For the past 14 years an extremely close friend of mine has had many unexplainable symptoms (lack of smell, muscle cramping, choking, extreme abdominal pain with nausea after eating fiber or fat-rich foods, etc.) This November 2015 I noticed a resting tremor in the arm on his left side. This was the first time I suspected his issues were related to one disease which might be Parkinson's Disease (PD). However, I still dismissed this possibility because tremors can be related to other medical issues (one of which is benign) and he has only had this tremor three times. Periodically over the past several months I noticed him walking slower, a frozen facial expression, and his right hand curled in front of him as if he had a stroke. On Dec 5, 2015 he really exhibited the slow walking, frozen face, and curled hand and he took forever to dress that morning. Later that evening I

became certain (in my opinion) that he has PD due to his telling me about a change in his handwriting which I did not witness. Unfortunately, he refuses to go to the doctor or seek medical help from a neurologist even when I told him I believe he has PD. On extremely rare occasions he'll go to see a particular specialist for whatever ailment is almost killing him at the moment. As a result, since December 2015 I've completely immersed myself in learning about PD with some cursory investigation of illnesses that exhibit Parkinson-like symptoms because I wanted to be sure I was on the right track. Besides searching the Internet for information, I purchased seven (7) books on Parkinson's Disease (PD) of which this book is one. My review is written from the perspective of someone who does not have PD but wants to learn about what the signs of PD are, what a person's life will be like, what are their challenges, what they should do about it, what is their life expectancy, etc. This book is in the list below. I've listed the books in the order of value to me and not in the order that I read them. I also put the copyright date of each book in parenthesis as well as my star ranking based on its usefulness to me and a short few sentences of what the book was about. If I had PD myself, I would rank them in a different order. I posted the same review to each one of these seven (7) books. At the end, I wrote a summary of what I think about PD and listed seven (7) other books I may one day buy and read.

Parkinson's Disease For DummiesÂ (c 2007) (4.5 stars) - Although this book does not have the latest developments or information on PD or Lewy Body disease (dementia included), it was invaluable in helping me understand what PD is in the most simplest terms. It helped me understand what to look for in a person with PD and what challenges they face. Since we are in 2016, the information on treatment is somewhat outdated. This book is great for someone who suspects they have PD or just got diagnosed because it clarifies symptoms in easy-to-understand language. It's a great resource for the newly diagnosed PD patient and those preparing for their first appointment. It also has information on Young Onset Parkinson's Disease (YOPD) and a chapter (sections of which I skipped over) full of exercises for the PD patient.

What Your Doctor May Not Tell You About(TM): Parkinson's Disease: A Holistic Program for Optimal WellnessÂ (c Feb 2003) (4 stars) - This is like a textbook on Parkinson's disease with case studies from actual patients and information on alternative therapies such as acupuncture. This book appears to outline all the symptoms of Parkinson'sÂ (TM)s, including ones not in other books such as Seborrheic dermatitis and stuttering (which is also in Wilson's disease). This book discusses everything from A-Z, like complementary medicine (homeopathy, acupuncture, etc.), issues for caregivers, etc. Case studies are interspersed throughout the text to give the reader a general idea of a PD person's experiences. It even mentions Mucuna pruriens which is a bean sold in supplement form and has high levels of levodopa that could be of help to PD patients--of course,

only take this with supervision of your doctor. A Caregiver's Guide to Lewy Body Dementia (c 2011) (5 stars) - this broadened my horizons about PD because it described the symptoms related to two very similar diseases and was co-written by someone whose spouse had dementia with Lewy bodies. PD is a Lewy Body disease where abnormal proteins show up on the part of the brain that controls movement. However, it is closely associated with Lewy Body Dementia that has abnormal proteins on the cognition part of the brain. Both diseases have many of the same symptoms and depending on which symptoms appear first that determines what the disease is called. It is either dementia with Lewy bodies (DLB) or Parkinson's Disease with Dementia (PDD). The diagnosis is critical because medications for one disease can have adverse effects on those with the other disease or on those with Alzheimer's. Some DLB patients are misdiagnosed with Alzheimer's and those medicines are contraindicated in most cases for them. It was this book that helped me realize the symptoms I was seeing was the same with my friend and also easily explained what a caregiver needs to do.

Living Well with Parkinson's (second edition) (c 1991, 2005) (5 stars) - This book was originally written by a woman who had Parkinson's Disease but who died on November 25, 1998 from a heart attack unrelated to PD. It was revised in 2005. This book is phenomenal in my opinion because it supplied me with an excellent narrative of what it was like to live with Parkinson's and how to make that life worth living. The chapter on "Medications and Therapies" provides a list of diseases that can resemble PD. The chapter on "Is There Life With Parkinson's" is a positive narrative on how the author lived very well with the disease.

Parkinson's Humor - Funny Stories about My Life with Parkinson's Disease (c2012) (4 stars) - is a lighthearted book written by someone who has PD. The book, although not very funny to me, educated me on what day-to-day life is like to live with PD. For instance, Beverly mentioned how sometimes she felt starched when describing the rigidity PD patients experienced. Except for Living Well with Parkinson's, this book was the only other uplifting book. All the others books were way too serious and sobering. At a time when I am new in trying to understand PD and PDD, reading a text like this or the one above was critical especially since I was overdosing on the subject. This book provided the mental break I needed, was slightly educational, and an extremely easy read.

Parkinson's Disease: The Complete Guide for Patients and Caregivers (c 1993) (3 stars) - this book is similar to What Your Doctor May Not Tell You About(TM): Parkinson's Disease: A Holistic Program for Optimal Wellness but it's 10 years earlier so the information is dated. For example in one chapter on how to cope with Parkinson's there's a suggestion to use a Dictaphone if you can't write. It has a short first section on symptoms of the disease and then goes into history, treatment, etc. There are three sections, however, that I found worthwhile. The Chapter on "The A to Z Guide to Symptoms and

Side Effects," "Planning Your Financial Future," and "Diseases That May Resemble Parkinson's Disease" which is in the Appendix II are invaluable. One thing I did not like about this book is that it was very negative describing more than once about the disabling effects of PD and how you have get your affairs in order, etc. Except for the three worthwhile chapters, I feel I did not need to purchase this book to get the information I was looking for.

Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease (c 2015) (4 stars) - the author is actually a PD patient and this book covers the most recent research on PD. It was not as helpful to me because it talked more about the latest developments in the search for a cure as well a brief glimpse at tests and drugs for PD patients. If I were a person with PD, then this book would probably be second in value in my list. For me, I could have done without purchasing this book.

In summary, what I discovered is that a PD patient does not die from their disease and they can have a normal life expectancy. PD is a slowly progressive disease, that is not usually hereditary, and which affects each patient differently. Not all PD patients have visible tremors. The disease definitely changes the patient's life and the lives of those closest to them but it sometimes does this for the better because the patients re-evaluate their lives and how they want to spend their time. For many, the disease will be an inconvenience that the patients and caregivers can learn to live with. There are no tests that can definitely determine someone has PD while the person is alive. A definitive diagnosis can only be made with post-mortem brain analysis. PD is determined via a process of elimination of testing for other similar diseases, observing arm muscle reactions during a test a doctor may try, and observing how the symptoms respond to Carbidopa / Levodopa drugs. It is critical that patients seek help immediately and partner with a doctor (or several doctors such as physical therapists, speech therapists, etc.) to seek a diagnosis and develop a treatment plan. At the early stages of PD, no drug therapy may be involved; it might be more of a wait and see approach. The positive attitude of the patient along with eating right, exercising, partnering with a healthcare team, and having a good support network provides the best outcome for the patient to have a fruitful life with only some limitations and modifications.

Please understand that no one book provided all the information I needed or wanted. I discovered information has to come from several sources, including the Internet and PD support groups. For instance, one PD symptom not mentioned in any of these books is gastroparesis. I found that one by searching the Internet with the word Parkinson's and abdominal cramping with nausea and the likes. I did these searches years ago, but at that time I did not suspect PD so Parkinson's was not part of the search criteria. I do hope my friend will seek the help of a neurologist, detail all his symptoms, and let me tell the neurologist what I have been seeing. Could I be wrong about believing that my friend has PD. Absolutely, I could be wrong; even doctors

misdiagnose patients. However, after reviewing Internet sources for the other diseases mentioned in these books, the only other diseases that come close with his symptoms are a brain tumor or Wilson's disease. However, with Wilson's disease his eye doctor would have noticed the copper ring (known as Kayser-Fleischer Ring) around his cornea during his eye exam. Although I am on PD overload, below are seven (7) other books (not listed in any particular order) that I might purchase in the future to learn more. The first one is on a disease with very close PD symptoms and the other six are on PD or a person's experience with PD.

1. Wilson's Disease for the Patient and Family: A Patient's Guide to Wilson's Disease and Frequently Asked Questions about Copper
2. The Muhammad Ali Parkinson Center 100 Questions & Answers About Parkinson Disease (100 Questions & Answers)
3. A Life Shaken: My Encounter with Parkinson's Disease
4. Lucky Man: A Memoir
5. Parkinson's Disease: A Complete Guide for Patients and Families (A Johns Hopkins Press Health Book)
6. Parkinson's Disease and the Family: A New Guide (The Harvard University Press Family Health Guides)
7. Eat Well, Stay Well With Parkinson's disease

My grandfather was recently diagnosed with LBD. I have just begun reading this book, but it has already provided me with so much knowledge about the journey he is going through. I want to do everything I can to help ensure he has a good quality of life as his cognition and motor skills deteriorate from this awful disease - this book gives me confidence that I will have knowledge to be his best advocate. I hope more books on this topic become available as more research is done. Thank you to the authors for thinking of the caregivers and writing this book for us!

My Dad has LBD. I highly recommend this book for any family member of an LBD patient. It is so helpful and explains conditions and terms in a very easy to understand format. We wish we would have had this book earlier in his diagnosis. We have asked the staff and caregivers at his assisted living to read it.

This book is informative and includes snippets of real experiences with those having this type of dementia. I liked reading the experiences. I especially liked the chapter on behavior management. Thank you for sharing your experiences and writing this type of book. I appreciate all the effort placed in researching and compiling this data. I read the book in a day and feel better prepared for how we will care for our family member and what to expect going forward.

As a writer, researcher, and caregiver for persons with dementia, I can say that this book is a wonderful guide. Lewy Body Dementia is unique from others I have read because it gives readers scenarios that all experienced dementia caregivers can relate to and support. I recommended this book to one of my client's family and to the other caregivers on the case. They were delighted when they bought the book. I just wish I had found it sooner. It is so important for caregivers to be able to share. We don't just have a job, we have a purpose and mission to help clear away the fog, give guidance through the forest of Lewy's and help slow down the roller coaster. I recommend this book to all families, health care professionals, EMT's, physical therapist and all those who work with persons who are taking this journey with some wonderful and priceless people.

I bought this book when I found out a good friend has this condition. I was going to visit her and wanted to be up on what to expect when I saw her. I am a hospice volunteer and never heard of this type of Alzheimer's. So glad I bought this and a bought one for her husband and mutual friends to help educate them. Knowledge is power.

It's been 5 months since my mother was diagnosed with Lewy Body Dementia, and this has been my go-to book time after time. I love having it on my Kindle so I can do a quick search for the information I need. Sometimes I need ideas, sometimes I just need the reassurance from the persona antidotes. It makes it easier to go down this road, knowing others have been there ahead of me. Well written and a wonderful resource for a disease that it out of the spotlight.

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A Caregiver's Guide to Lewy Body Dementia Dementia with Lewy Bodies and Parkinson's Disease Dementia: Patient, Family, and Clinician Working Together for Better Outcomes Going the Distance: Caring for a Loved One with Lewy Body Dementia Lewy Body Dementia: Information for Patients, Families, and Professionals Lewy, Mom, and Me: a caregiver's story Caregiver Triumphant: How to overcome stress and thrive in your role as a family caregiver An Unintended Journey: A Caregiver's Guide to Dementia What If It's Not Alzheimer's?: A Caregiver's Guide To Dementia (3rd Edition) The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocognitive Disorders (Guides to Caregiving) Let's Talk Dementia: A Caregiver's Guide The Alzheimer's Medical Advisor: A Caregiver's Guide to Common Medical and Behavioral Signs and Symptoms in Persons with Dementia BODY BUTTER: Homemade Body Butter Recipes - 30 DIY Body Butter Recipes For Softer, Healthier, And More Radiant Skin (Body Butter, Body Butter Recipes, natural remedies) Love in the Land of Dementia: Finding Hope in the Caregiver's Journey

A Loving Approach to Dementia Care: Making Meaningful Connections with the Person Who Has Alzheimer's Disease or Other Dementia or Memory Loss (A 36-Hour Day Book) Thoughtful Dementia Care: Understanding the Dementia Experience The Dementia Handbook: How to Provide Dementia Care at Home Finding Grace in the Face of Dementia: "Experiencing Dementia--Honoring God" Your Body, Yourself: A Guide to Your Changing Body (Your Body, Your Self Book) The Bath and Body Book: DIY Bath Bombs, Bath Salts, Body Butter and Body Scrubs Intermittent Fasting: Make Your Body Burn Fat For Fuel Everyday, Optimize Muscle Mass, Hormones And Health. Decrease Insulin Resistance And Body Fat (intermittent ... fasting for weight loss, lean body.)

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