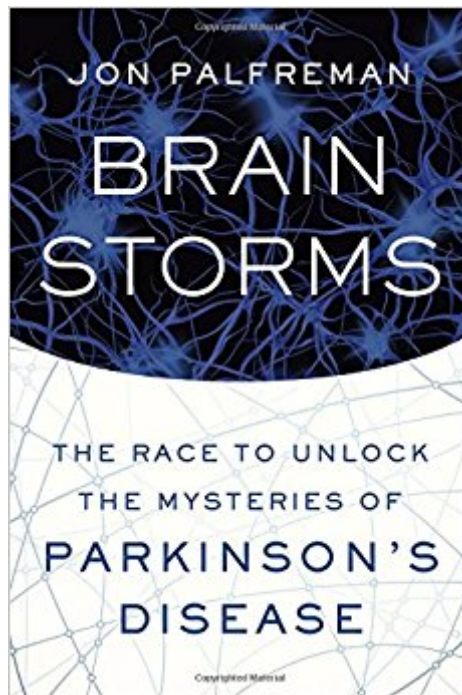




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# Brain Storms: The Race To Unlock The Mysteries Of Parkinson's Disease



## Synopsis

A Top 10 Science Book of Fall 2015 - Publishers Weekly A star science journalist with Parkinson's reveals the inner workings of this perplexing disease Seven million people worldwide suffer from Parkinson's, and doctors, researchers, and patients continue to hunt for a cure. In *Brain Storms*, the award-winning journalist Jon Palfreman tells their story, a story that became his own when he was diagnosed with the debilitating illness. Palfreman chronicles how scientists have worked to crack the mystery of what was once called the shaking palsy, from the earliest clinical descriptions of tremors, gait freezing, and micrographia to the cutting edge of neuroscience, and charts the victories and setbacks of a massive international effort to best the disease. He takes us back to the late 1950s and the discovery of L-dopa. He delves into a number of other therapeutic approaches to this perplexing condition, from partial lobotomies and deep brain stimulation to neural grafting. And he shares inspiring stories of brave individuals living with Parkinson's, from a former professional ballet dancer who tricks her body to move freely again to a patient who cannot walk but astounds doctors when he is able to ride a bicycle with no trouble at all. With the baby boom generation beginning to retire and the population steadily aging, the race is on to discover a means to stop or reverse neurodegenerative conditions like Parkinson's and Alzheimer's. *Brain Storms* is the long-overdue, riveting, and deeply personal story of that race, and a passionate, insightful, and urgent look into the lives of those affected.

## Book Information

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## Customer Reviews

2016 PROSE Award for Outstanding Scholarly Work by a Trade Publisher (Honorable Mention)

“[A] lucid overview . . . Extraordinary case studies abound.

“Well written and poignant . . . Mr. Palfreman has written a clear, compelling account of this important disease . . . The reader will appreciate his courage in looking death in the face and candidly assessing the situation of himself and others caught in the grasp of this complex malady.

“Nicholas Wade, *The Wall Street Journal*

“Well-written and informative.

“Orla M. Smith, *Science*

“Brain Storms is well worth checking out, whether you are a new or old patient, a significant other of someone with Parkinson’s disease, or simply a curious reader, as the book is as much about the science of the disease as it is about the brave people living with it . . . Jon also writes about his own journey as a patient, and does so with captivating candor, curiosity, and inspiring hope.

“Anna Tan, *Parkinson’s News Today*

“[Palfreman] has an excellent grasp on the science behind the disease . . . but it is as a human story that the book is most compelling.

“John Hardy, *The Times Literary Supplement*

“A deftly crafted and authoritative literary journey . . . As a PD sufferer myself, I found Brain Storms both uplifting and deeply informative. But if at bottom, what you want out of a science book is clean prose, clear thought and fascinating stories, Palfreman delivers.

“Doug Clifton, *Miami Herald*

“Palfreman follows Parkinson’s history from the careful observations of 19th century physicians to today’s cutting-edge research. [He] relates complex research studies as gripping medical mysteries . . . Ultimately, Brain Storms is about more than Parkinson’s disease; it’s about the people living with the disorder.

“Sarah Schwartz, *Science News*

“In his latest book, Brain Storms, [Palfreman] invites readers along as he seeks to understand the neurodegenerative disorder through the eyes of the researchers working every day to uncover vulnerabilities in the disease’s rapacious progression . . . And the journey is not a dispassionate one; it is imbued with [Palfreman’s] sense of urgency.

“Bob Grant, *The Scientist*

“Award-winning journalist Palfreman’s fast-paced, captivating, and crisp narrative of patients, doctors, and researchers is part scientific investigation, part medical detective story, and part memoir, and it opens wide a window into the world of Parkinson’s.

“Publishers Weekly (starred review)

“[A] well-researched history and overview of the current state of research. Palfreman brings his skill as a science writer and a deep personal commitment to . . . this illuminating book.

“Kirkus Reviews

“Perhaps there is no one better suited to putting a story of medical and scientific research into context than award-winning journalist Palfreman . . . The information is

clear, careful, dotted with the personal experiences of Palfreman . . . and hopeful.

Booklist "[A] story that unfolds like a confounding mystery, replete with missteps, promising leads, red herrings and amazing discoveries . . . [Palfreman] has a gift of explaining complex molecular processes in clear, understandable terms. What is ultimately appealing is the 'just-around the-corner' prospect of solving this mystery making you marvel at what is possible.

David Takami, The Seattle Times "The best and clearest book I've encountered on the current state of knowledge about Parkinson's Disease . . . [Palfreman is] a master storyteller and fluent writer with a great eye for revealing stories and details.

The Tampa Tribune "[Brain Storms] is both a deeply personal memoir as well as an incredible example of superb scientific journalism . . . Palfreman does an exceptional job of describing the history of the illness . . . and the status of ongoing efforts to develop more effective treatment options for those afflicted.

Bowling Green Daily News "Brain Storms is a sweeping survey-and a fascinating discovery narrative-of one of the great neurological scourges of our time. In this era of brain science, Jon Palfreman's book points to remarkable vistas of research that promise hope to millions.

Sandeep Jauhar, New York Times-bestselling author of Doctored and Intern "Through keen and captivating storytelling, Jon Palfreman expertly shares the many challenges and opportunities that surround Parkinson's research and gives credit to the people who have made drug discovery and development possible-most of all, the individuals living with the disease.

Todd Sherer, PhD, CEO of the Michael J. Fox Foundation for Parkinson's Research "Rarely if ever does a book on Parkinson's disease come along that so seamlessly explores the personal side of the illness as well as the latest in scientific research from around the world. Jon Palfreman presents the disease with insight, sensitivity, and accuracy-truly an awesome achievement. Whether you are a patient, family member, physician, scientist, or simply someone interested in how science and emotions merge when someone develops a disease such as Parkinson's, you will benefit enormously from this eminently readable, wonderful book. I have never seen a book that explores the whole story of Parkinson's disease in such depth, and with such skill.

J. William Langston, MD, Chief Scientific Officer and Founder of Parkinson's Institute "In Brain Storms, Jon Palfreman highlights the intriguing personal stories behind the expanding clinical picture of Parkinson's disease and the recent advances in Parkinson's research. The book is brilliant-and riveting.

John Nutt, MD, Director Emeritus of the OHSU Parkinson Center "Jon Palfreman combines the skills of an incredibly talented science journalist with the passion of someone who is also affected by Parkinson's disease. His book is an amazing

inspiration for all of us involved in Parkinson's disease research. We hope that he will have cause to write another chapter soon, one that highlights a cure. —Patrik Brundin, MD, PhD, Van Andel Research Institute—  
“Brain Storms is a fascinating journey from the discovery of Parkinson's to new treatments on the horizon-informative, inspiring, and, since Jon Palfreman's quest to understand the disease is personal, poignant. This book is essential reading for all who will, in one way or another, confront disability and disease in their own lives.” —R.

Douglas Fields, author of *The Other Brain*

Jon Palfreman, Ph.D., is a professor emeritus of journalism at the University of Oregon. He is an Emmy, duPont, and Peabody Award-winning journalist, a Nieman Fellow, and the recipient of the Victor Cohn Prize for Excellence in Medical Science Reporting. In addition to producing more than forty primetime documentaries for the BBC and PBS, Palfreman is a coauthor of *The Case of the Frozen Addicts* and *The Dream Machine*. He lives in Lexington, Massachusetts.

Brain Storms is an excellent overview of the discovery and research (as of the end of 2014) on Parkinson's Disease, written for people who have been diagnosed or are close to someone who has Parkinson's. Jon Palfreman is that most valuable of persons, a layman who has written the book he wished he had found. Brain Storms is easy to read (Palfreman is a teacher of journalism), written in a compelling narrative non-fiction style. It will give you the history and context to understand patients, care-givers, doctors, and researchers who are dealing with Parkinson's. My only criticism of the book is that there is no chapter dealing in depth with dementia. Although only a relatively small percentage of Parkinson's patients develop dementia, it is a tremendous tragedy and a huge problem for the families to whom it happens. It appears that many neurologists are focused on movement symptoms and are slow to recognize cognitive problems, although there are medications that can be effective. Mr. Palfreman's book does make clear that Parkinson's and Lewy Body Disease are the same thing, Parkinson's primarily in the midbrain that controls movement, LBD primarily in the cortex that controls cognition. If you need information on dementia, Googling "Lewy Body Disease" will put you in touch with a community of experts and family members who have shared their experience and learning. Mr. Palfreman's book makes the connection that will give you confidence you're on the right track. I hope Mr. Palfreman will update this book regularly. It is an important contribution to the layperson's understanding of Parkinson's Disease.

I have Parkinson's disease. This book gave me a great insight into ALL aspects and how it has and

will affect me in the future. No sugar coating, no nonsense, no avoiding the grim realities.....just the unvarnished truth as it is know today.A must read for those with the disease and care givers!

Written uniquely well...covers the science, research and pathology of the disease in sufficient depth, but also reminds one of the human dimension and what it is to live with this diagnosis.

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 DummiesÃÂ (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 Wellness** (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'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 other 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 to 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 as 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

Jon Palfreman has written an excellent book. I, however, have no qualifications to make such a judgement. I am not an expert in the field but I am a Park (someone with Parkinson's). The author is

a science journalist who is a Park himself. What we are exposed to is his efforts to thoroughly investigate what is the status of research and drug development in the fight to eventually eliminate Parkinson's. We are taken on a rollercoaster ride in covering the highs and lows of the human effort to not only master Parkinson's but mastering the entire brain as well. He provides the reader with a context to place the current status in by covering the historical encounters with what was called the shaking Palsy. I'm not going to review all the author's coverage of the efforts to ameliorate the malady; let me just say that he holds no punches and tells the story as it is and not as it would if viewed through rose colored glasses. He does however, end with positive news about an approach that he feels will change the world for all the sufferers of brain degeneration. Sent from my iPad

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Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease Happy Brain: 35 Tips to a Happy Brain: How to Boost Your Oxytocin, Dopamine, Endorphins, and Serotonin (Brain Power, Brain Function, Boost Endorphins, Brain Science, Brain Exercise, Train Your Brain) Everything You Need to Know About Caregiving for Parkinson's Disease (Everything You Need to Know About Parkinson's Disease) (Volume 2) A Parkinson's Primer: An Indispensable Guide to Parkinson's Disease for Patients and Their Families The Muhammad Ali Parkinson Center 100 Questions & Answers About Parkinson Disease (100 Questions & Answers) Parkinson's Humor - Funny Stories about My Life with Parkinson's Disease Cook Well, Stay Well with Parkinson's Disease - Super Foods for Super People with Parkinson's Storms in Amethir Books 1-3 Omnibus: (Storms in Amethir Epic Fantasy Series) Gum Disease Cure (Gum Disease Cure, Periodontal Disease, Gum Disease, Gum Infection, Gingivitis treatment, Tooth Decay) The Gum Disease Cure: How I cured Periodontal Disease in 2 months (Gum Disease Periodontal Disease Periodontitis Receding Gums) Kidney Disease: for beginners - What You Need to Know About Chronic Kidney Disease: Diet, Treatment, Prevention, and Detection (Chronic Kidney Disease - Kidney Stones - Kidney Disease 101) Making the Connection Between Brain and Behavior: Coping with Parkinson's Disease Delay the Disease -Exercise and Parkinson's Disease (Book) Welcome to Spiralizer World: Unlock EVERY Secret of Cooking Through 500 AMAZING Spiralizer Recipes (Spiralizer Cookbook, Vegetable Pasta Recipes, Noodle Recipes,... ) (Unlock Cooking, Cookbook [#4]) Welcome to Spanish Food World: Unlock EVERY Secret of Cooking Through 500 AMAZING Spanish Recipes (Spanish Food Cookbook, Spanish Cuisine, Diabetic Cookbook in Spanish,...) (Unlock Cooking [#19]) Welcome to Japanese Food World: Unlock EVERY Secret of Cooking Through 500 AMAZING Japanese Recipes (Japanese Cookbook, Japanese Cuisine, Asian Cookbook, Asian Cuisine) (Unlock Cooking, Cookbook [#7]) Welcome to Korean Food World: Unlock EVERY Secret of Cooking Through 500

AMAZING Korean Recipes (Korean Cookbook, Korean Cuisine, Korean Cooking Pot, Asian Cuisine...) (Unlock Cooking, Cookbook [#8]) Welcome to Filipino Food World: Unlock EVERY Secret of Cooking Through 500 AMAZING Filipino Recipes ( Filipino Cookbook, Filipino Recipe Book, Philippine Cookbook) (Unlock Cooking, Cookbook [#27]) Welcome to Chinese Food World: Unlock EVERY Secret of Cooking Through 500 AMAZING Chinese Recipes (Chinese Cookbook, Chinese Food Made Easy, Healthy Chinese Recipes) (Unlock Cooking, Cookbook [#13]) Welcome to Wok World: Unlock EVERY Secret of Cooking Through 500 AMAZING Wok Recipes (Wok cookbook, Stir Fry recipes, Noodle recipes, easy Chinese recipes ,...) (Unlock Cooking, Cookbook [#2])

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