
A LIFE

Shaken

*My Encounter
with Parkinson's Disease*



JOEL HAVEMANN

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with Parkinson's Disease*

Joel Havemann

FOREWORD BY STEPHEN G. REICH, M.D.

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Notes to the Reader

This book is not meant to substitute for medical care of people with Parkinson's disease, and treatment should not be based solely on its contents. Instead, treatment must be developed in a dialogue between the individual and his or her physician.

In view of ongoing research, changes in governmental regulations, and the constant flow of information relating to drug therapy and drug reactions, the reader is urged to check the package insert of each drug for any change in indications and dosage and for warnings and precautions.

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To Judy,
who made it all happen

And to Anne, Margaret, and William,
who make it all worthwhile

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Foreword

I HAVE HAD THE PRIVILEGE OF SERVING as Joel Havemann's neurologist since February 5, 1990. But his book has made me feel more like an obstetrician. I have seen it mature from conception, through early development, and, now, delivery. This book has two parents, both found in Joel, and each has contributed something unique. The first is a professional journalist who has written an objective, detailed, lucid account of Parkinson's disease—in my view, the best by a non-physician. The reader looking for accurate information on Parkinson's will find it here. The second parent is a middle-aged husband and father who, just as he seemed to have the world by the tail, had his grip loosened by Parkinson's disease. Joel's personally revealing account of living day-to-day, and year-to-year, with Parkinson's disease is the soul of this book. It is a story told vividly and passionately with all the highs and lows, fears, frustrations, insights, struggles, victories, and losses—big and small—faced by those with Parkinson's disease.

For Joel, as for all people with Parkinson's disease, the news of the diagnosis was tragic. He was truly *shaken*. And yet, while there is a background of tragedy in the pages that follow, this story can and should be viewed as a tale of heroism. When, as Joel relates, the simple act of flipping a pancake presents a challenge, it is easy to appreciate the perseverance and courage needed just to get up every day determined to live as normal a life as possible. Joel, like multitudes of others with Parkinson's, does so. And he, like others similarly affected, probably doesn't consider himself a hero. But doing the ordinary under extraordinary limitations is undeniably heroic.

Overly humble, Joel does not reveal in this book that he was one of several recipients of the first, and now annual, "Buddy Awards," presented at a fundraising gala for Parkinson's in 2000. This award, named after Barton "Buddy" Levenson, another remarkable patient of mine, embodies the determination, integrity, equanimity, and optimism he demonstrated in a long battle with Parkinson's disease.

Joel recounts the details from his first visit to me on February 5, 1990. I, too, despite seeing many patients, have a clear memory of that visit. Tall and thin (read on for his gentle account of my own, rather opposite, physiognomy), he impressed me with his background as a Harvard

mathematics graduate and his current position as a senior editor with the *Los Angeles Times*. I could also tell he was scared to death—that “deer in the headlights” look that, after fifteen years of practice, I have never grown accustomed to and hope I never will. By the time a person with Parkinson’s disease makes it to the trained eye of a Parkinson’s specialist, the diagnosis is usually obvious in the waiting room. That’s the easy part. The hard part is delivering the diagnosis. In the back of every new patient’s mind is the hope that maybe the problem is a ruptured disk or nerves or benign essential tremor—anything but Parkinson’s.

The diagnosis of Parkinson’s disease, especially in young people like Joel, usually sets off a spiral of worst-case scenarios. No amount of reassurance on my part seems to help at this stage. But slowly, and remarkably, people with Parkinson’s and their families learn that there is life after the diagnosis. Fortunately, the disease progresses slowly, and at least for the intermediate future, anti-parkinsonian medications do a pretty good job of controlling the symptoms.

Successful management of Parkinson’s disease depends on more than just taking medications. On a daily basis, I have the privilege of observing people like Joel cope amazingly well. From them, I have developed an acronym that I hope will help readers with Parkinson’s and those who care for someone with the disease: HOPE for coping. The *H* stands for honesty and humor. Honestly facing the diagnosis of Parkinson’s and willingly sharing it with others are cornerstones of effective coping. Just after being diagnosed, Joel went so far as to have his situation posted on the computer bulletin board at work. This prevented rumors and, by demonstrating that the subject was not taboo, helped to avoid pity from co-workers. Not everyone is so forthcoming so quickly. Every person has to find the appropriate time to share the diagnosis with family, friends, and colleagues. After doing so, many patients have expressed their relief to me. Although there is nothing funny about Parkinson’s, as you’ll see in Joel’s book, humor, the second characteristic of successful coping, can be a potent antidote, particularly when the alternative is crying—which is not a bad coping strategy, either, from time to time.

The *O* in HOPE stands for optimism. Viewing the glass as half-empty or half-full may be more innate than learned or cultivated, but successful coping with Parkinson’s relies on emphasizing the small victories and de-emphasizing the defeats. For example, it would have been easy for Joel to bypass an opportunity to spend three years in Brussels

reporting on the European economy, but he took the chance and his accomplishments overshadowed the tribulations of Parkinson's.

Perseverance is the *P* in HOPE and another quality I see in those who manage to cope well with the disease: they simply don't give up. When getting out of bed in the morning, putting toothpaste on the toothbrush, and getting dressed take extra time and effort, it would be much easier just to stay in bed. But successful copers persevere, determined to lead as normal a life as possible and view obstacles not as insurmountable but as challenges.

For the *E* in HOPE, I'm preaching to the converted. Readers of this book are already arming themselves with one of the most potent weapons in the battle against Parkinson's: education. Understanding the disease, the medications, and the latest research helps to provide a sense of control. I find it much easier and more productive to treat an educated patient; the doctor-patient relationship, so important for a chronic disease like Parkinson's, becomes one of teamwork rather than paternalism. You will find in these pages an up-to-date account of Parkinson's disease which strikes a perfect balance between enough sophistication to make it credible and meaningful and enough of the journalist's touch to make it readable and understandable.

Since 1989, when Joel first developed Parkinson's disease, tremendous advances have been made: no fewer than half a dozen new drugs; a renaissance in surgical therapy; the discovery of several genes causing Parkinson's; considerably more public and private funds available to fight Parkinson's; the growth and preeminence of the Parkinson's Study Group, a consortium of investigators in North America devoted to experimental therapeutics; new discoveries in the laboratory on the basic mechanisms underlying the death of dopamine nerve cells; and exciting leads about what causes Parkinson's. And this is just a partial list. As Joel's book poignantly demonstrates, and as other people struggling with Parkinson's know equally well, there is still a long way to go. But I am optimistic that it will not be long before this book, and others on Parkinson's, will be found in the history section of libraries and bookstores.

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Acknowledgments

NO ONE WITH PARKINSON'S DISEASE can lead a fully independent life. As the symptoms accumulate, we depend more and more on others—family, friends, co-workers, others with Parkinson's, even sometimes strangers—to help us manage the routine tasks that slowly become unmanageable on our own. So it has been with this book. I couldn't have compiled these chapters without considerable help from the experts: the medical professionals, the Parkinson's community, and others. I thank them all.

At the beginning I had no idea how difficult it would be to learn, let alone explain, the way the brain works and the way the Parkinson's brain doesn't work. Helping me along the way were some of the best teachers in the land: Roy Bakay, Ted Dawson, Valina Dawson, Roger Duvoisin, Curt Freed, John Gearhart, Philip Gildenberg, Mark Hallett, Frederick Lenz, Ken Marek, Harold Mars, Ron McKay, Mihail Polymeropoulos, Ira Shoulson, Lisa Shulman, Joseph Steiner, and William Weiner. I owe a special debt to Fred Wooten, head of neurology at the University of Virginia, who helped me through some particularly rough spots, and to Elisabeth Leach, who linked us up.

Then there are the people with Parkinson's who generously shared their experiences with me: the activists, Perry Cohen, Jim Cordy, and Joan Samuelson; the politician, Janet Reno; and the many whose stories are so inspirational and instructive: Ed Calhoon, Tom Collins, Art Cook, Sandra Forney, Stephanie Fromer, Rusty Glazer, Barbara Gormly, Dana Gunnison, Stan Hamburger, Sam Joseloff, Nina King, Michael Kushnick, David Laventhol, Larry McCurdy, Lisa Mummert, Don Nelson, Leon Paparella, and Sandra Pollock. And a tip of the hat to Becky Dunlop, who set me up with many of the above.

In the category of caregivers, Parkinson's unsung heroes, I benefited from the experiences of Donna Dorros, Susan Hamburger, and Carolyn Nelson. A special thanks to Morton Kondracke, who wrote the book about caregiving (*Saving Milly*) and who helped me launch mine.

The *Los Angeles Times* gave me, no questions asked, the time I needed to complete the manuscript. Thanks in particular to Jack Nelson and Dick Cooper for giving me their encouragement and to Doyle

McManus and Tom McCarthy for putting up with my peculiar habits. Among the health journalists who shared their ideas and information with me were Marlene Cimons, Sheryl Stolberg, and Aaron Zitner.

Thanks to those who read all or parts of the manuscript and provided both encouragement and constructive criticism—not always an easy combination. Two Parkinson’s patients, Rusty Glazer and David Laventhol (a former publisher of the *Los Angeles Times*), read passages and gave me boosts at crucial junctures. At the Johns Hopkins University Press, executive editor Jacqueline Wehmueller championed my cause and offered sound advice. Alice Porter, a dear friend, read a draft from start to finish and offered a particularly coherent critique. John Alexander, a good friend, gave me a historian’s perspective. Bunli Yang, a friend indeed, not only provided editorial guidance but also, by being there when the going got rough, helped keep me going.

Finally, my special thanks to three who are in categories all their own.

Stephen G. Reich of the Johns Hopkins University played two essential roles. As Dr. Reich, he defied the maxim that neurologists don’t care about their individual patients. His personal attention is responsible in no inconsiderable degree for the fact that I’m still active nearly twelve years after he diagnosed my Parkinson’s. And as my friend Stephen, he read every chapter as I completed it and corrected misstatements and misinterpretations. If the book in the end is moderately optimistic about the outlook for those of us with Parkinson’s disease, it’s because he said countless times, “Well, it’s your book, but I really don’t think you have to be quite so downbeat.”

Bob Samuelson managed to cement his position in my very small circle of close friends even while playing the indispensable role as exacting editor of the manuscript. He was able (could he have learned from his own Judy?) to find kind ways to say, “You call this a chapter? Where’s the rest of it?” and, “You’ve got the information, but nobody will ever be able to tell that if you present it this way.” No writer ever built up a greater debt to a colleague than I to him.

And finally there is my family: Ethel Ellersiek and Bruce Bohle, who shared their experiences with me and read and critiqued an entire draft of the manuscript; Theresa Nicol, Edward Herskovits, and little Evelyn, who taught me about small quantities of spices and small packages of joy; and of course, Judy and our children. Anne, Margaret, and William may never really know me other than shaky; I hope they also know me as strong. Judy made the book possible by leaving me lots of room and

time to write. She read the manuscript from front to back at least twice and offered a valuable mix of editorial and spousal advice. But those comments trivialize her contribution. She is more than I could have asked of life, and I love her dearly.

A Life Shaken

Introduction: *As I Lay Trembling*

The disease, respecting which the present inquiry is made, is of a nature highly afflictive. . . . The unhappy sufferer has considered it as an evil, from the domination of which he had no prospect of escape.

—James Parkinson, *An Essay on the Shaking Palsy*

THIS DAY SHOULD BE PRIME TIME FOR ME. It's the first Monday in February 1997: President Bill Clinton is sending his annual budget to a hostile Congress. As a senior editor in the Washington bureau of the *Los Angeles Times*, I oversee the stories that our reporters are writing about Clinton's budget. At 6 P.M., three hours before the deadline for punching the computer button that sends our stories to Los Angeles, I should be coiled at my keyboard, honing the stories that will appear in more than a million newspapers in southern California tomorrow under a bold headline extending across most of the top of the front page.

Instead, I'm flat on my back on a couch that's too short in a windowless room in the bureau. I can't even sit at a computer, much less make a keyboard work. My arms and legs are shaking uncontrollably. Although I am only 53 years old, I have already been struggling with Parkinson's disease for seven years. And right now the disease is winning.

I take one of the tablets that are supposed to suppress the symptoms, hoping that this one will be more effective than the last. Then I stretch out, my head awkwardly perched on one arm of the couch. To restrain my shaking legs, I wedge my feet up against the opposite arm. Likewise, I tuck my arms under my back. Neither strategy works. The muscles in my legs and arms become rigid to the point of pain. I have to move them to release the pressure. Then they go right on shaking. I attempt to concentrate on something other than my body. It has to be something complicated enough to capture my attention without making me worry. I try counting by thirteens in French. *Treize*, I say to myself as I try to take a deep breath. *Vingt-six*. *Trente-neuf*. After five or ten minutes, this begins to help. At last, somewhere around 650 (13 added to itself 50 times), I begin to relax.

Then the switchboard operator announces on the office loudspeaker, "Telephone call for Joel Havemann. Joel, you have a phone call." I have no intention of taking the call. But just thinking about it upsets my