JOSEPH H. FRIEDMAN, MD

MAKING THE CONNECTION BETWEEN
BRAIN & BEHAVIOR

COPING WITH
PARKINSON’S DISEASE

SECOND EDITION

“A must-read for all whose lives are touched by this illness.”

—Dr. Hubert H. Fernandez, MD
Head of Movement Disorders, Center for Neurological Restoration, Cleveland Clinic, Cleveland, Ohio
Making the Connection Between Brain and Behavior

Published by Demos Health
Making the Connection Between Brain and Behavior

Coping with Parkinson’s Disease

Second Edition

Joseph H. Friedman, MD

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My patients, whose courage, resilience, and fortitude are a never-ending source of inspiration

and to:

Meg, whose loyalty, sensitivity, capability, intelligence, work ethic, and devotion has been the foundation of our efforts to improve the treatment of Parkinson's disease.
“How do you know it’s a hallucination, if you see them outside your house?”

“Well, every morning I see a group of nuns, wearing habits, building me a deck.”
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As a neurologist, I was trained to think of Parkinson’s disease as the prototypical movement disorder. As a patient, I learned it was much more. It is an often debilitating cognitive behavioral disorder which also has sensory and physical manifestations.

Quality of life for people living with Parkinson’s disease depends largely on better management of these behavioral issues. In Making the Connection Between Brain and Behavior: Coping with Parkinson’s Disease, Dr. Friedman focuses on these aspects in great detail. He also focuses on the interactions between the person living with Parkinson’s, his or her social environment, and the consequences to the family unit.

This book is not only for Parkinson’s patients and their caregivers, but also for their physicians. The good physicians will strive to master the slowness, the rigidity, the tremor, and the postural imbalance. The excellent physicians, like Dr. Joseph Friedman, will focus on the whole patient—including the psyche—the depression, the delusional thinking, the dementia, and the common demoralization. These can dishearten and undermine even the strongest among us. But there is hope to be found in this book.

The publication of Making the Connection Between Brain and Behavior: Coping with Parkinson’s Disease is a source of great hope to all who battle the “shaking palsy” every day of their lives.

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Preface

This book is intended for lay people with Parkinson’s disease (PD) as well as those who care about someone with PD. It is written at a level for people who have little or no scientific or medical knowledge.

I have tried not to water down the material. I hope that it is not too simple for sophisticated nonphysicians in medical fields, or too technical for others in nonmedical fields. Technical terms are used but are explained. There is a glossary. Vignettes will be used to illustrate common problems. There are only general discussions of treatment approaches because these vary so much from individual to individual. Practical advice and common sense are my guiding principles. I hope to address all the common behavioral problems that PD patients and their families encounter.

This book is intended to be a source of practical information. It will hopefully not contain inflammatory advice. All opinions of the author will be clearly stated as such, to avoid conflating my own ideas with those of the general PD community. If there are opposing opinions, I will mention them.
Introduction to the First Edition

All serious diseases affect families and a network of individuals. It is much like the hub of a wheel. Cancer, heart disease, ulcerative colitis, emphysema, psychiatric disorders, and an untold number of other conditions alter interpersonal dynamics in a large number of ways. The person’s independence may be affected. One day the family head, the main bread winner, may suddenly find him- or herself to be in need of assistance instead of the other way around. The person everyone counted on suddenly needs help.

When the tables turn the stresses can be enormous. And while many of these stresses may be obvious, such as for a single parent who supports three children and develops PD, just as the oldest is getting ready to apply to college, some can be subtle or downright surprising. Some of the PD patients who had deep brain stimulation became so much better after their surgeries that they went from being almost completely dependent on their spouse, to being completely independent and sometimes well enough to return to work. And while that is obviously a wonderful miracle, some families actually fell apart as a result.

The caregiver whose main role in life was defined by the ill PD patient suddenly has nothing to do, no role in the family, no one to supervise. All of a sudden, he or she is an “empty nester.” While such problems are uncommon, I mention this to show that people’s responses to changes may not be predictable. Behavior is a complex thing, and we all need humility in attempting to deal with it. Nevertheless, there is a lot we do know about behavioral changes in PD, although there is even more to learn.
This book represents a distillation of more than three decades of experience with PD patients and their families. I wrote this out of a sense of obligation, partly from my love and respect for my patients and their supporters, partly because I love my work, and partly because I think that my own personal intellectual journey depicts a tale that is educational for patients as well as for doctors.

As I tell my patients: When you get older you don’t get any smarter, but if you’re lucky and you work hard, you may get wiser. I began my PD career as a strong believer that PD was a disease of the motor system and everything else was of secondary importance. James Parkinson himself noted that “the senses and intellect” were untouched. That turned out to be wrong. Behavioral issues are as much a part of the disease as tremor. But, more importantly, I’ve come to recognize the role I play in my patients’ lives. From the occasional letter of thanks that I’ve received from family members after a patient died, I learned that simply being there was my central function.

I was the doctor who received the call about some new ailment. Was it due to PD or was it due to something else? I was the one who reassured patients that they weren’t “crazy” because they were seeing children in the backyard who weren’t there. I was the one who told them that the aching discomfort in the shoulder or the back was due to PD or that the stabbing pain in the abdomen was not due to the PD. I could reassure them that they were doing well and that we would work together.

The fact that I was part of the “team,” that I was “on their side,” that I could put their personal journeys into a general context was of the greatest importance. In their worlds, they were unique. When patients touched base with me they renewed acquaintanceship with the wider world of PD. Their symptoms were validated. “Oh, so other PD patients have that problem too.” And I learned that my knowledge about drugs and how to manage the various clinical motor problems was actually less important than simply being an anchor in a stormy sea. I learned that emotional problems were as “real” as shuffling and falling. I learned that too many of my colleagues spent their time on
Introduction to the First Edition

the motor aspects of PD, that is, the movement and balance problems, and not enough on the behavior issues, which were often even more troubling.

When we think of a “disease” we usually think we know what we’re talking about, but when we look at people with PD we see a rather wide spectrum of problems. Some people have tremor while some don’t. Some are stooped, some freeze, some can’t talk, and so on. James Parkinson is justifiably famous because he saw the threads that connected all of these disorders and thought they were different manifestations of the same underlying condition.

What most doctors, even neurologists, don’t realize is that while we use motor dysfunction to diagnose PD, it is actually the behavioral problems that cause the most devastating consequences of this illness. It took me many years to recognize this, and when patients and families face these behavioral problems they feel surprised and alone because they always thought that PD caused tremors, and not much else.

Published studies have clearly shown that the most important problems causing nursing home placement of the PD patient is not slowness or the inability to walk. They are psychiatric. Similarly, the most stressful problems for caretakers are behavioral, not motor. It is more stressful to care for a PD patient who can walk independently but has behavioral problems than a PD patient who is wheelchair bound but without behavior problems.

The reader must keep in mind that all people have unique behaviors and that not everything that “goes wrong” or changes is due to the Parkinson’s disease. The reader must also be aware that our understanding is in flux. It took 20 years before anyone made a connection between gambling and dopamine agonists. It took over 150 years before REM sleep disorder was recognized in PD. What are we missing today?

Twenty years ago there was very little written about the behavioral aspects of PD. Some authorities wrote about depression, but whole problem areas were virtually terra incognita. Twenty years ago the first papers on treating psychosis appeared. Fifteen years ago the
sleep problems of PD were first explored. Dementia, the most difficult and devastating of all the problems, has only been a significant research target for the past decade. Naming and identifying a problem makes it easier to discuss. Confirming that behavioral changes are part of the disease process make it more likely that patients and families will reveal these changes to their doctors, just as they ask about their various aches and pains and changes in bowel and bladder and the various other bodily functions.

There is no reason to read this book in the order presented. Most people with PD will find that only some of the chapters apply to them. Few will find that all of the chapters apply.

I will be happy to hear from readers with their suggestions for modifying future editions, should there be a strong enough interest to justify writing one. I am confident that much of what I write will become dated in a few years, but since much of this book reflects common sense, that part will not go out of date.
Introduction to the Second Edition

Since the first edition of Making the Connection Between Brain and Behavior was published in 2008, I have received a lot of positive feedback. And, thankfully, there has been no negative feedback. This book has helped many people and by updating and expanding it for the second edition, I hope to help many more.

Each chapter has been revised. In some cases the changes were minute; in others they were extensive. I’ve also added three chapters (16–18) and two appendices (C, D). The new chapters address three of the most common issues I am currently asked about now. The appendices do not address the behavioral aspects of PD, but I wrote them in the belief that they would be helpful to people struggling with the difficulties of PD, and they were widely distributed in the PD community in the United States. The chapters that were updated, unfortunately, did not require as much revision as I would have wished. I regret to tell you that advances in treatment have been modest since the first edition. On the other hand there has been a dramatic increase in the appreciation that neurologists now have for the behavioral aspects of PD, and all knowledgeable neurologists are aware that behavior changes are as much a part of PD as the changes in movement. This is due to the increasing numbers of scientific papers addressing the behavioral problems of PD, underscoring their importance, and the greater attention these areas have been getting in the medical community.

Advances in clinical medicine require interest, intelligence, and resources. Creativity is helpful, but not necessarily required. There are many talented, interested, and intelligent doctors keen on
improving the treatment of PD. Unfortunately, resources are limited. There are few funds available to subsidize the very expensive clinical trials required for testing new treatments, and, you may be amazed to read this, but we often have trouble finding PD patients willing to participate in research studies. In a study of antidepressants in PD that ended earlier this year, major academic centers had difficulty recruiting even two subjects per year. The study was successful, but had to stop only halfway through due to the problem of getting PD patients to volunteer. This is not a unique situation.

So, there have been no “breakthroughs” since the first edition yet progress has been made. We have a much better grasp on the impulse control disorders associated with dopamine agonists. The neurological community has a much greater understanding of the importance of behavioral aspects of PD, both in terms of their frequency and in terms of their importance in quality of life. Patients and their families are better informed and demand better care. We finally have data demonstrating that depression can be treated successfully in PD.

But many things are still left to do. The battle goes on. For those who live the battle every day, it is hoped that this small contribution will at least lighten the load a little.
Making the Connection Between Brain and Behavior

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Overview

Behaviors in people develop in complex, poorly understood ways. From studies of patients with Parkinson’s disease (PD), we know that certain types of behaviors are considerably more common in PD patients than in the general population, forcing us to conclude that these behaviors are related to the disease. In some cases the problem is part of the disease, due directly to the involvement of certain brain cells. In other cases the problem may be due to the physical disability and represents a “reactive” process, that is, the mind’s reaction to having the disease in the first place. An overview is provided of some of the major topics concerning behaviors in persons with PD.

We all see the world differently. Our experiences are unique and ever-changing so that our behavior changes as we mature. Some individuals seem to change less than others, which is usually perceived as a negative thing, a sign of inflexibility, as if the person has failed to adapt to changes in the environment. We like to think that age produces wisdom, as experience increasingly alters our perceptions of the world.
Sometimes there is little adaptation. We see older people developing relatively fixed behaviors that don’t change from year to year. Their schedule becomes their religion. But behavior is always in some degree of flux, if for no other reason than the environment is always changing.

PD is a defining trait. Most people do not have it, so that having it puts one in a minority and thus singles one out as being different from one’s peers, friends, and relatives. It colors the lives of both the patients and their families. One cannot choose to not change. Some changes that occur may be nonspecific, or even just appear with normal aging, but some changes occur so frequently that doctors who specialize in PD think there is probably a connection either with PD itself, the medications used to treat PD, or possibly just the uncertainty of the future due to the vagaries of how PD progresses.

Most PD experts would say that behavioral changes that occur during this disease are due to both primary brain changes and the patient’s reaction to having the disease. The basic personality of the patient determines how the various disabilities of PD, the sudden change in one’s future plans, and the insecurity of the future affect the person’s psyche. For example, will the person, faced with a disability or an attention-grabbing tremor, “give in” by withdrawing from the world, or “fight back” by refusing to compromise his or her lifestyle? Will someone work as long as possible, or get disability as soon as possible? Will the onset of PD trigger a rush to do all the things planned for retirement for fear of not being able to do them when the planned time arrives, or will it trigger the opposite, the giving up of all plans and various vacations or adventures? Optimists behave in one way, pessimists in another. “Realists” react in one way, and “deniers” bury their heads and act as if there is nothing wrong.

There are a number of behavioral issues that occur in PD, some of which are unique to PD, or almost so, while others may be fairly generic across the range of neurological or even just progressive, incurable, potentially disabling medical disorders. To make a point and be very specific, let me briefly introduce two fascinating behavioral
issues in PD, one of which is relatively specific to PD, and the other of which is seen in virtually all medical disorders.

Rapid eye movement (REM) sleep behavior disorder (RBD) (see Chapter 12) is seen almost only in PD or dementia with Lewy bodies (see Chapter 7), or in multisystem atrophy, which are all closely related disorders. In RBD, patients, typically male, act out their dreams by punching or choking their bed partners. This is due to PD and is not a drug-related behavior. It is due to specific pathological changes in the brain. It is specific to only a small number of diseases.

Fatigue is very common in PD, causing more disability than most other common symptoms. Yet fatigue also affects almost all patients with significant anemia, congestive heart failure, cancers of all types, hypothyroid disease, sleep disorders, lupus erythematosis, multiple sclerosis, and a multitude of other disorders. Fatigue often occurs, for no understandable reason, in otherwise healthy people, but is much more common and often more severe in almost every medical, neurological, and psychiatric disorder, with the lone exception of mania. Still, fatigue is an integral part of the PD syndrome. Patients usually did not have it before they developed PD, and in some cases fatigue developed long before patients realized there was anything else wrong with them other than a lack of energy.

So, PD patients may have very unusual and specific problems, such as RBD, or commonplace problems that many other people also have. Just because fatigue is common to many disorders does not mean that it is not also “specific” to PD, by which I mean that it is associated with a variety of other symptoms, may have a different cause, and may respond to different forms of treatment than fatigue in other disorders.

Some of the behavioral changes in PD are due to medications, but most are not.

The two most troublesome complications of PD are dementia and psychosis. Dementia is not caused by the drugs used, although they certainly may contribute. By dementia, we mean an irreversible process that results in impaired memory and thinking. About 30% of
PD patients have impaired memory and thought processing, which we believe is part of the disease process and is not due to medications. With time, the chance of this developing increases. While these changes are different from those seen in Alzheimer’s disease, there are some similarities. Psychosis is the term given to a major change in thinking, in which hallucinations and delusions are common, often causing impaired reality testing. This problem is generally caused by the anti-PD medications, but dementia may bring with it some of these problems as well, causing an increased difficulty in the treatment, as you will see in Chapter 7.

Sleepiness and sleep disorders are probably as common as constipation in PD. Excessive daytime sleepiness may arise from untreated PD or as a complication of some of the PD medications, particularly the dopamine agonists, pramipexole (Mirapex), ropinerole (Requip), and rotigotine (Neupro).

Depression, anxiety, apathy, and fatigue are probably the most common of all behavioral aspects of PD, yet little is known about any of them. Depression, anxiety, and fatigue are common in the general population and even more so in any population of sick people. But these are serious problems to the PD patient because they have such a deleterious effect on quality of life. Depression is usually treatable, but there are virtually no data to guide the treatment of anxiety, fatigue, or apathy.

There has been much discussion, but very little research, about the so-called parkinsonian personality, by which is meant a relatively rigid, obsessive, and humorless person who does little for fun and lives out the “Protestant ethic” of a life filled with hard work. Despite more than 60 years of hypothesizing, we still do not know how much of these beliefs are myths and how much may be true.

A 65-year-old woman moved to a new house to better accommodate her disability. She developed problems sleeping through the night, depression, and severe kyphoscoliosis (a spine condition).

Treatment with one selective serotonin reuptake inhibitor (SSRI)
antidepressant was not very helpful, and something was prescribed to help her sleep. She started seeing a psychologist who provided “talk therapy” and also suggested a change from one SSRI to another. Her PD medications were not changed. As she began to sleep through the night, her depression and anxiety improved and her posture became almost erect. She got her energy back, stopped having backaches, and felt like a new person. Even though her medications often wore off, she did not develop a terribly stooped posture anymore. Her PD support group friends continually asked her, “What did your doctor put you on to help your posture so much?”

This is a wonderful and true example of how the behavioral and motor aspects of PD intermingle. Very often if one aspect of the person’s situation improves, other aspects do as well. In this case it was unclear to the patient and her doctors whether the improved sleep helped the depression and anxiety, whether the improved depression helped the sleep and anxiety, or whether the improved anxiety helped the sleep and depression—but the one thing that all agreed on was that whatever improved her sleep, depression, and anxiety helped her posture since there was no change in her anti-PD medications.

A 68-year-old man with a 10-year history of PD suffered from uncontrollable clinical fluctuations, with uncomfortable or disabling dyskinesias during about 25% of the day, and severe “off” periods for another 25% of the day. He refused to consider deep brain stimulation. A variety of medication adjustments were not helpful. On one office visit, he reported that he had been on vacation for two weeks and during that time he had virtually no off periods and the dyskinesias were not troubling. In fact, he was able to use a ladder to climb on and off a boat and go sailing without any problem, something he had been unable to do for the previous two years. When he returned home to Rhode Island, however, he
was as bad as he had ever been, although he had made no change in his medication regimen.

The influence of psychological effects is profound in PD. Tremors resolve with relaxation and worsen with stress. People freeze if they think others are looking at them. People who freeze may unfreeze if they step over lines on the ground. One of my teachers used to say that the first person out of a chair in an emergency is the patient with PD who can’t get out of the chair if you ask him to.

A recently recognized set of problems arising from the treatment of PD includes compulsive activities, particularly gambling, but also shopping, hypersexual activity, eating, and many other things as well (see Chapter 11).

The final point to make in this overview is that the more we study PD the more we learn, much of which is so obvious in retrospect that we often wonder how we were not able to see it for so long. Now that PD is increasingly recognized as a neurobehavioral disorder, and not just a movement disorder, we see these behavioral aspects receive increased attention and better treatment.

If you have a behavioral problem that you have not yet discussed with your doctor, you should do so. You will not know if it is part of PD until you ask. You may be the one to get your doctor to recognize that this problem is, in fact, a common problem in PD that has simply gone unrecognized. Helping your doctor to recognize the problem in you may alert him or her to the same problem in other PD patients.