

A Handbook for People with
Parkinson's Disease

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INTRODUCTION

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This handbook is for people with Parkinson's disease (PD) and their families. We have based it on our philosophy that one has control over how Parkinson's disease affects one's life. A person can either give up and live in despair, or can fight back believing that through education, support, and maximizing personal strengths, life will continue to have meaning and richness.

"Fighting back" begins with the understanding that health-care decisions are made in partnership with one's health-care provider. To be a partner, one must learn as much as possible about Parkinson's disease, medications, and non-drug therapies so that a person can be his or her own best advocate and participate in the decisions that uniquely affect the self.

On the other hand, we do not believe that a person needs to know everything about PD. Just because a person has Parkinson's disease does not mean he or she will experience all possible symptoms. Too much information can be overwhelming and cause unnecessary anxiety. For this reason we have designed this notebook in modules, each dealing with a different aspect of PD. Be selective in what you read. Choose the topics that are pertinent to you and your symptoms.

The editors of this handbook are nurse clinicians who have cared for people with PD and their families for many years. We live on opposite sides of the United States and want this handbook to reflect a philosophy and professional wisdom that spans the continent.

We would also like to thank our colleagues who have contributed to the expertise of this handbook in special areas. We believe that education and a positive attitude are powerful weapons against this disease and we hope that this handbook will provide the reader with both.

WHAT IS PARKINSON'S DISEASE?

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Parkinson's disease is a progressive neurologic disorder affecting 1 in 100 people over the age of 50. Typically the diagnosis is made in the sixth or seventh decades of life, with approximately 7% of people diagnosed before the age of 40.

DIAGNOSIS AND SYMPTOMS

Diagnosis is made on the basis of signs and symptoms found on physical exam. There are no diagnostic tests for Parkinson's disease. If tests such as an MRI scan or blood work are ordered, these are usually done to rule out other possible disorders.

There are primary and secondary symptoms of Parkinson's disease. When symptoms first appear, they are very mild and sometimes intermittent. As the disease progresses the symptoms become more pronounced and more persistent.

The primary symptoms are tremor, rigidity, bradykinesia (slowness), and impaired balance. It is important to know that not all symptoms need to be present to make the diagnosis. Tremor is most prominent when a person is sitting quietly and improves or disappears when the person is using their arms or legs. That is why Parkinson tremor is described as a resting tremor.

Rigidity is stiffness of muscles. In the early stages of disease this can be mistaken for arthritis or bursitis. As the disease progresses, the stiffness is perceived as a cramp or tired, aching muscles. Depending on the location, a person might describe back pain, headache, or a "charley horse" in the leg. This rigidity is associated with the flexion posture characteristic of Parkinson's disease. Rigidity responds well to a combination of medications and a vigorous stretching program. (See the chapter on exercise.)

Bradykinesia means slowness of movement. Fine movements, such as fastening buttons or writing, becomes more clumsy. Another manifestation of bradykinesia is loss of associated movements. These are movements outside of one's awareness: blinking the eyes, facial expression, swallowing, swinging the arms, and changes of posture. The overall appearance is one of unusual stillness when a person is sitting quietly.

Bradykinesia also affects voluntary movement. This can be seen as a hesitation in starting movement, such as getting up from a chair or a momentary arrest of movement when one is turning or entering a small space such as a doorway. Medication can be very helpful in improving bradykinesia.

Impaired balance occurs because of a change in postural reflexes. These are the reflexes that facilitate rapid changes in the center of balance when walking or standing. A person will notice a feeling of unsteadiness and in later stages of disease may have a tendency to list to one side or the other and may even fall backwards or forwards. Medication is less helpful for balance problems than for rigidity or bradykinesia. Physical therapy can be very helpful in teaching safety maneuvers, balance exercises, and providing consultation regarding ambulation aids.

The secondary symptoms of Parkinson's disease may affect some but not all people. These include changes in bowel and bladder function, speech and swallowing, fatigue, mood and memory, sexual function, and sleep. Please see other modules for information on these symptoms.

CAUSE

Parkinsonism is the loss of dopamine-producing cells in an area of the brain stem called the substantia nigra. These nerve cells project fibers to areas deep in the brain called the basal ganglia. The function of the neurochemical, dopamine, is to allow nerve impulses to run smoothly along these fibers and transmit messages to muscles of the body -- producing what we know as "normal" movement. When the supply of dopamine is decreased by approximately 80% the symptoms of Parkinson's disease emerge. Over time the loss of dopamine-producing cells continues and symptoms become more severe. Although much research is being done in this area, the cause of this cell death is still unknown. The current debate is whether nerve cell loss is something that has a genetic link occurring slowly over time or happens suddenly after being exposed to a toxic substance. It may be a combination of these two theories. It has been suggested that some people are genetically predisposed to developing Parkinson's disease and therefore more susceptible to the potential damage of a toxic exposure.

PROGNOSIS

Parkinson's disease is a progressive disease. The rate of progression varies, making it difficult to give patients and families definitive information that can provide them the comfort of knowing what to expect and how to prepare for their future. The studies that have attempted to describe the prognosis of Parkinson's disease have been hard to interpret because drug therapy treats the symptoms -- obscuring the degree of underlying severity.

Following are some generalizations about prognosis which may provide some understanding and direction to patients and families.

1. Parkinson's disease progresses slowly. Disability is the major concern for patients and families.
2. Current drug therapy treats the symptoms but does not change the rate of progression.
3. The average length of time from diagnosis to levodopa therapy is 3½ years.
4. Drug treatment, specifically levodopa therapy, slows the onset of disability.
5. Disability will eventually occur and increase while on therapy but this is usually because of the emergence of new symptoms that do not respond to levodopa. The symptoms that have responded to drug therapy continue to be responsive.
6. Levodopa has potential side effects that can limit the amount of drug used -- and therefore the potential benefit. (See Medication Module)
7. Practically speaking, families should plan for their future. A lawyer who specializes in elder law can help plan for one's financial future and minimize the expense of chronic illness. People who are still employed should look at their work and consider how Parkinson's symptoms might alter performance and think of ways to modify their work environment or their type of work. As an example, a newly diagnosed trial lawyer decided to pursue a position as a judge because there was less public speaking and his tremor would be less noticeable.

8. It is also important to remember that current research offers tangible possibilities that could change the course of Parkinson's disease. Gene therapy, surgical therapies, and drugs that delay progression hold great hope for changing the disability of Parkinson's disease.