

**A Guide to Parkinson's Disease for  
the Family and Friends of the Patient**

**This booklet expresses only the personal opinions of the authors and is not intended to offer medical advice. Always consult your personal physician for medical advice.**

This booklet is distributed by National Parkinson Foundation Central & Southeast Ohio Chapter, a non-profit organization serving those afflicted with Parkinson's Disease, their partners and families. The society publishes a monthly newsletter with information for both patients and caregivers as well as establishing local support groups. Completing the form inside the back cover will add your name to the list of those of us fighting Parkinson's disease. If you reside in central or southeast Ohio, we can put you in contact with a nearby support group.

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You are, no doubt, reading this because someone in your family or a friend has Parkinson's disease (PD). Over one million people in the U.S. suffer from PD, yet most of us know very little about it. This booklet describes its symptoms, discusses treatments, and gives you advice about how you can help the patient.

It is very difficult to accept a long-term condition that intrudes upon your life. Your loved one is making that effort and is learning to deal with PD and the limitations the disease will impose over time. That person wants you to know more about PD so you will be able to accept and adjust to the problem as well.

The better we all understand PD, the better the patient, caregivers, friends, and family can cope with the disease and manage its treatment. Our goal is to maximize the quality of life for all concerned. All too often those with PD are unnecessarily embarrassed by its symptoms and avoid going out in public. The fact that someone has given you this booklet is an indication that they are accepting that they have PD and are going to fight the disease and live life to the fullest. Applaud their actions and give them your full support. Many, many PD patients continue to lead full, productive lives. George H. W. Bush intends to parachute from an airplane at age 95. Billy Graham still writes and preaches. Michael J. Fox still works in TV and the movies. Muhammad Ali, not only the most recognized person in the world, but also has worked for Parkinson's causes. All have PD.

Staying active, staying involved with people, and routine exercise are all very important for people with PD. Do all you can to assist and encourage them in remaining active.

***“The availability of family members who are able to provide both practical assistance and emotional support is one of the best predictors of success in effectively managing a chronic and progressive illness such as Parkinson’s disease.”***

*The Comprehensive Management of Parkinson’s Disease,” 1995, Demos Vermande Publications, NYC Chapter 14 by Robert G. Feldman, MD, Peter Mosbach, Ph.D., Cathi-Ann Thomas, RN, MS, and Linda M. Perry, RN M.Ed.*

## **What is Parkinson’s Disease?**

The brain normally produces a substance called dopamine that serves as the connection between the “will” and the muscle. When you want to move any part of your body, dopamine is the substance used to send the message from your brain to the muscle to make it move. In PD, for some unknown reason, a small, pea-sized section near the brain stem stops producing enough dopamine and those messages are not transmitted adequately. The patient has difficulty controlling his or her body. This is why PD is called a “movement disorder”.

PD is frequently called an “old person’s disease”. The fact is that the average age of diagnosis is 57, with one third under 50, one third between 50 and 60, and one third over 60. Younger people may be diagnosed early in the progression of the disease and continue to work in their profession and carry on other activities for many years.

Currently, there is no cure for PD, but there are treatments. A number of prescription drugs, and even some surgical procedures, help the patient control or reduce the symptoms. In today’s world of modern medicine, the life expectancy of a Parkinson’s patient is only slightly less than normal.

Before we describe the various symptoms, there are some important facts you should know. First, PD is definitely not contagious. It is not possible to get PD through any type of contact with a patient. The next concern of family members is the question of whether PD is hereditary. This question is being heavily researched at present and the complete answer is not known. Leading scientists believe that there may be a “genetic predisposition” to PD. By this they mean that some genetic defect may make it easier for PD to establish itself, but by itself does not necessarily caused PD.

## What Are the Symptoms of PD?

Parkinson's patients joke that PD is a "designer" disease because each patient seems to have a unique set of symptoms. Since PD affects the body in a number of ways, it brings along a large number of symptoms and difficulties. Not all patients exhibit all of the symptoms.

The three main symptoms of PD are tremor, muscle rigidity, and bradykinesia (the medical term for slowness of movement). Let's discuss each.

First is tremor, the rhythmic shaking of limbs or other parts of the body. In fact, PD used to be known as the "shaking palsy", which is what James Parkinson was describing in his paper of 1817 that led to its being called "Parkinson's Disease".

This shaking is usually seen in the hands and arms, sometimes only on one side of the body, sometimes on both. While it is usually most pronounced when the arm is at rest, it can interfere with eating, fastening buttons and other tasks that involve small-motor skills.

Tremor is embarrassing to the patient, especially when eating in public. There are many small ways to help, such as not filling cups and glasses to the brim. Help is often needed in cutting food, especially meat. If you are eating at home, you can serve food already cut up.

Tremor also makes it hard to do such things as buttoning clothing. Adapting clothes with Velcro will enable the patient to be more independent, especially for such tasks as bathroom chores.

Bradykinesia is the medical term for the slowness of movement, which is usually seen in parkinsonians because of the lack of dopamine needed to complete movement. In its extreme form, the patient may "freeze", being unable to move at all for a time. This freezing phenomenon often happens when walking.

There are drugs that help control both tremor and bradykinesia. Patients are **SOMETIMES** troubled by these problems when they first wake up in the morning before they have taken their first dose of medicine, and toward the end of their dosage schedule when it is time for more medicine.

Often patients perform a task one minute and then find themselves "off" and unable to repeat the task shortly thereafter. Although the patients have no control over this phenomenon, it often surprises and confuses their helpers.

Obviously, you need to allow extra time for activities with parkinsonians. Not allowing enough time and putting pressure on the patient to do things faster induces stress, which makes the problem worse.

While you walk without giving it conscious thought, patients usually must concentrate on walking and its components. Walking and talking at the same time may be overloading the patient. Be sensitive of this.

A number of strategies may help overcome freezing. They include putting something on the floor for the patient to step over or giving verbal cues. Ask the patient what works for him or her.

The third principal feature of Parkinson's is muscle stiffness and rigidity. The classic parkinsonian has what is known as the "Parkinson's stoop". The head is bowed, and it becomes difficult for the patient to turn it from side to side. This has obvious safety implications when walking near traffic so you will have to be extra mindful.

Part of this stiffness is shown as a lack of, or the minimizing of, facial expressions. This is called "mask" by the doctors. Often people interpret mask to mean that the patient is unhappy or ungrateful when this is not the case. The patient is merely unable to exhibit the usual and expected facial expressions. Strangely enough, this may be one of the hardest aspects of the disease to deal with when the patient is a loved one. We get so used to all of the non-verbal communication that ordinarily comes from facial expressions that we make incorrect assumptions from the blank looks we receive due to the disease. Patients can help by verbalizing feelings that were formerly expressed by a smile, raised eyebrows, or the like.

The three main symptoms of PD can be controlled to some extent by medication. **It is very important that medication be given on schedule.** Delay in taking medicine can cause a patient to "turn off" or have severe tremor problems. It is important that you plan ahead. If you are traveling by auto, for instance, make certain you have water and medicine available and watch the time. Attending movies, plays, and sporting events pose the same challenge.

There are pill boxes now available that sound an alarm at the designated times. These pill boxes may be found at many pharmacies.

Another timing problem with medication can be meal times. Sinemet, and other levodopa drugs, are absorbed by the intestines using the same mechanism that absorbs protein. Generally, these drugs should be given half an hour before eating so their effect is not delayed. Some patients may also need to consider a low-protein diet. The physician is always your best source of information of this topic, but you should be aware of this problem.

## Other Symptoms

Many other problems are caused by PD. Adding to these problems are a number of others caused by the side effects of the medications prescribed. Here again, and especially here -- not all patients have all of the symptoms.

## Soft Voice

A Parkinsonian's voice usually becomes softer and less audible as the disease progresses. Strangely, the patient feels that he or she is speaking as loudly as ever.

You'll have to listen more attentively and arrange seating so that you will be able to hear. Also, encourage the patient to exercise the voice daily by shouting or singing loudly in the shower.

## Dyskinesia

Dyskinesia is the medical term for the writhing or twisting and jerking of various body parts that is sometimes seen in PD patients. This is almost the opposite of freezing. With dyskinesia the connection between the brain and muscle is "stuck" in the open position. Sometimes this is due to overmedication and only lasts for awhile.

Because this is very noticeable, it is embarrassing to the patient, who cannot control it. Be accepting of it; there is little else you can do.

## Shuffling Walk, Balance Problems

PD patients often walk leaning forward, head down, with rapid, short stutter steps due to problems they have with balance. Doctors call this walk "chasing their center of balance". Walking like this takes a lot of extra energy and often results in falls. The result is that too many PD patients limit their walking and do not get enough exercise.

To help with this problem, the first thing you should do is to make the environment safe. Remove any loose throw rugs (their feet don't lift high enough to avoid getting tangled up in them). Move furniture so that there are adequate passageways. Pad sharp edges on furniture with which they might come in contact.

Because balance problems can cause serious falls, stairs should have railings on both sides. Try to avoid waxed floors and glass windows, doors, or tables into which the patient could fall.

Once a PD patient gets out of balance, their body cannot signal muscles to react fast enough to save them from a fall. That same slowness also means they will not be fast enough to bring arms or hands up in time to break the fall.

Patients living alone should have some way to call for help if they fall. This could be as simple as carrying a small portable phone or as complex as paying for an elaborate signaling pendant that communicates with a home security system.

## Swallowing Problems

It is not uncommon for the patient to have problems swallowing. Sometimes this manifests itself in drooling. This, too, is embarrassing to the individual and not controllable.

Swallowing difficulties sometimes make it difficult to take medicine. One common solution is to drink half a glass of water before taking the pills and the other half after. Cutting food into bite-sized pieces helps.

## Constipation

The bowels slow down along with the rest of the body. Increased transit times result in very hard stools and constipation. Constipation is not just an unpleasant side issue with PD; it can be a life-threatening issue. PD patients are advised to drink eight full glasses of water a day and eat high-fiber foods and plenty of fresh fruit and vegetables.

Visiting parkinsonians should always be given water or other liquids. If the patient is to drink enough water to prevent constipation, they need to be sipping almost continually.

## Dementia

Having PD doesn't preclude having other health problems. PD patients often have illnesses unrelated to PD. About 20% of PD patients develop a form of dementia with symptoms similar to Alzheimer's. This is called Parkinson's Plus. Dementia is defined as a loss of intellectual abilities severe enough to interfere with social or occupational functioning.

## Increased Emotional Expression

Although not adequately documented by researches, every parkinsonian I know reports that his or her emotions are more pronounced and “on the edge” Grown men with PD will sometimes cry when they hear news reports of tragedies, for example, and there are also reports of excessive laughing. For some patients, this is embarrassing.

## Depression

PD patients often suffer bouts of depression. This depression may be due to feelings about PD or problems with brain chemistry. Either way, depression can be dangerous. Clinical depression is more than feelings of grief or sadness; it is a medical problem that may require treatment. Neurologists can treat this condition with medication—**In reality, we can initiate treatment, however if severe usually defer to psychiatrist.** Many primary care physicians will treat and follow depression. Make sure the patient discusses any depression with his or her doctor.

## Insomnia

Many, many patients have trouble getting enough sleep. Lack of sleep sometimes leads to mental confusion and feelings of being exhausted.

## Progression of the Disease

Parkinson’s is a progressive disease, meaning that it tends to get worse over time. The rate of progression varies greatly and cannot be predicted. The medicines prescribed to control symptoms become less effective over time. Dosages may have to be increased and new drugs introduced.

The best way to fight the progression of the disease is to exercise and stretch daily, and to remain involved with people and to continue normal activities. A proper diet high in fiber with plenty of water is essential as well.

Rigorous adherence to the medication schedule and routine doctor visits are very important.

Don’t allow the patient to give up or wallow in self-pity. Joining a Parkinson’s support group will provide both the patient and the care partner with both support and additional coping skills.

You may call the telephone number listed inside the front cover of this booklet to learn about Parkinson support groups in your area.

## Types of Treatment

While there is no “cure” for PD at present, medical researches are searching not only for a cure but also for different treatment strategies to minimize the symptoms.

### Medicines

Various drugs can be prescribed to improve the levels of dopamine in the brain. Some drugs provide a substance directly converted into dopamine, others make the receptors more sensitive so that less dopamine is needed, others slow down the body’s re-absorption of dopamine. Most of these drugs become less effective over time and the patients doctors will adjust medications from time to time.

### Surgery

Presently several surgical procedures are used in treating PD. Standard procedures to minimize disabling tremor include the pallidotomy that surgically destroys a small part of the brain causing the problem. Deep brain stimulation uses a pacemaker-like device to cancel the incorrect messages being sent by that section of the brain. Deep brain stimulation is a less invasive procedure that can be reversed if necessary.

### Special Needs

An area of special need is helping the patient who is hospitalized. Our members have reported a number of instances where very unpleasant, and sometimes potentially dangerous, incidents occurred during hospitalization.

A common problem of our current senior generation is that they were raised to respect and follow the advice and instructions of authorities, especially doctors. In today’s busy hospitals it is important that patients be aware of exactly what is happening during the treatment, what drugs they are being given, and what drugs they should be given and when.

A member of our society recently entered the hospital for hip surgery. She told the doctor doing the operation about her PD and assumed she would be given her medication. At the hospital, when she was not given her routine pills, she assumed that the medication must have been added to her IV. It took her several very uncomfortable days before she asked and found out that they were not giving her the medicine she needed. As a caregiver or family member, you should question anything you do not believe is right.

Medicine delayed, or even given too soon before or after a meal, is medicine that cannot do its intended job. Even though the staff may not like it, ensure that medicine schedules are rigorously adhered to and that a hospital's feeding schedule does not conflict with the proper interval between dosing and eating.

Some drug interactions involving some Parkinson drugs are not widely known. An especially important one is the potentially dangerous interaction between Eldepryl and Demerol. If you are taking Eldepryl, inform your physician and question any person giving you an injection.

This authority-questioning problem, which is not limited to seniors, is also evident in dealing with doctors. Make certain the patient takes the time to fully understand what the doctor tells him or her and that all questions are answered. It helps if a caregiver can be a part of those discussions so another pair of ears can hear and interpret instructions. Don't be afraid to question any health professional or to say you don't understand and need a further explanation.

## Resources

The most important resource if you are going to be a caregiver is a Parkinson's support group. There are support groups for patients that also have meetings for caregivers. Support groups provide the opportunity to meet with fellow patients and caregivers to share experiences and information.

## Summary

PD is a progressive neurological disease of unknown origin. It is definitely not contagious. Typically, PD is seen later in life but it does occur in younger adults. The average age of diagnosis is 57. Life expectancy after diagnosis is only slightly reduced and many continue to lead active, fulfilling lives.

PD patients may exhibit many different symptoms. Some can tend to be debilitating. Drugs are used to control or ease some of these symptoms but the timing of taking these drugs can be critical. Missing a scheduled dosage can result in freezing (inability to move) or increased tremor. Even if there are no outward signs of a missed dosage, the patient often experiences unpleasant "internal tremors". Travel and outings require planning and watching the time so that medication can be taken on time.

Memory problems often trouble PD patients. Often this is simply due to advancing age. Providing the patient with written lists of chores and activities will reduce the frustrations on both sides.

It is important that you always deal with the patient as directly as possible. Talk to the patient directly and do not answer for him or her. Often a waiter in a restaurant will ask something like, "What will he have?" Tell the waiter to ask your companion directly.

Respect the individual's desire to remain independent as long as possible. Our society members report that giving up independent living in their home and foregoing driving are among the hardest decisions they must make. Living environments can be modified to allow patients a longer period of independence.

Always remember that a PD patients lack of normal facial expression is a symptom of the disease and not necessarily what they feel in their hearts.

It is tough dealing with a chronic disease that affects your every waking moment. Encourage your family member to remain a contributor the the life of your family group and society as a whole. Do not allow them to withdraw from society, to wallow in self-pity, or to become clinically depressed.

Research on finding a cure is progressing on several fronts. Those of us with PD fully expect a cure will be found during our lifetimes. In the meantime, with you help, we will continue to fight the disease and keep our bodies in shape for the cure when it comes.

Thank you for reading this and for your help.





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Do you belong to a Parkinson's Support Group?  Yes  No

If not, would you be interested in joining?  Patient Support Group

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*The National Parkinson Foundation Central & Southeast Ohio Chapter does not charge annual dues, relying instead on donations. Our services are freely given to any patient or caregiver requesting help without any consideration of income. Many patients are elderly and on fixed incomes with high prescription expenses and cannot afford to give. We need your help.*

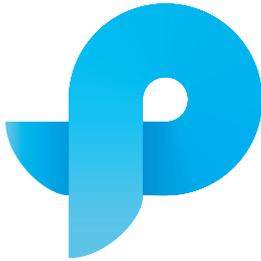
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Rev. 06/13