



# PARKINSON'S DISEASE

A GUIDE FOR PATIENTS AND FAMILIES



Featuring Michael J. Fox



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American Academy of Neurology

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## INTRODUCTION

Parkinson's disease (PD) affects the way your brain controls your muscles. This can make it hard to walk and do many other kinds of movement. More than 1 million people in the US alone have PD. And every year, about 40,000 people learn they too have the disease. If you or a loved one have been diagnosed with PD, you are not alone!

PD most often affects older adults, but about 1 out of every 10 people with the disease is younger than 45. Usually, PD symptoms start slowly and gradually get worse. But how a person feels, and how quickly the disease gets worse, can vary a lot from person to person. That's why it's important to see a neurologist if PD is suspected.

Although PD cannot yet be cured, being treated with medicine can help reduce some of the symptoms. Today, people with PD may live many years with the condition.

There are a number of things you can do to help manage PD and continue your daily activities. This booklet and DVD can help. You'll learn more about PD and how it is treated. Working closely with your health care professionals, and making healthy choices in your daily life, are important steps to coping well with the challenges of Parkinson's disease.

### DID YOU KNOW?

**Neurologists** are doctors who specialize in disorders of the brain and nerves.

**Movement disorder specialists** are neurologists who have studied an additional one to three years in a movement disorder program, or specialize in treating people with Parkinson's disease and other movement disorders.



## WHAT CAUSES PARKINSON'S DISEASE?

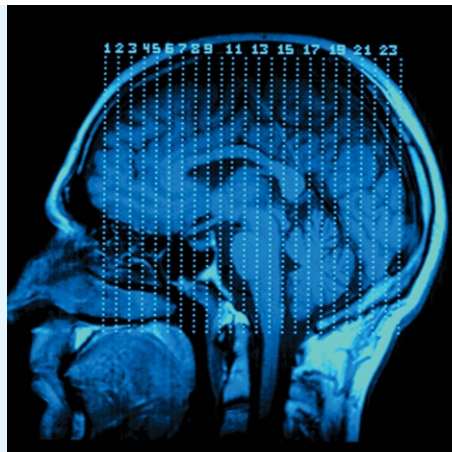
Doctors and researchers still have much to learn about Parkinson's disease. For 9 out of every 10 people with PD, no clear cause can be determined.

Even though the root cause of PD is usually not known, doctors do know a lot about how the disease affects the brain. PD causes a slow loss of a certain type of brain cell. These cells produce a chemical called *dopamine*, which helps control movement. When about 60% to 80% of these cells are lost, dopamine levels drop so low that movement-related symptoms appear. Shaking, stiffness, and slowness of movement are some common symptoms. For reasons that are still not clear, men are somewhat more likely to get PD than women.



### DID YOU KNOW?

**Dopamine** is a chemical messenger in the brain. It helps you control your ability to move.



## HOW DO I KNOW IF I HAVE PARKINSON'S?

There is no foolproof test for Parkinson's disease. No blood test, brain scan, or x-ray can prove for sure that a person has PD. Instead, the disease is diagnosed by certain signs and symptoms.

### There are four classic symptoms of PD:

- Tremor (shaking) when a limb is at rest, most commonly in one hand
- Slow movement in the arms or legs
- Stiffness of the arms or legs
- Loss of balance

### Other possible signs of early PD include:

- Small handwriting
- Difficulty with tasks that require fine control, such as buttoning a shirt
- Slow walking, dragging of a foot, or decreased arm swing when walking

When the disease worsens, a person may have a hard time balancing. He or she may also trip or fall frequently.

Not everyone with PD has all these symptoms. Some people have symptoms for years before they are properly diagnosed.





Patients with PD may also have symptoms that do not involve movement or their muscles. These symptoms may include:

- Difficulty with thinking and memory
- Depressed mood
- Loss of the sense of smell
- Difficulty with sleeping
- Constipation
- Sexual dysfunction
- Pain or discomfort in arms or legs

As you can see, PD is a complex condition. It can also be challenging to treat. That is why it is best to be diagnosed and treated by a neurologist or movement disorder specialist. You can find a neurologist or movement disorder specialist in your area through some of the groups listed in the Resources section at the back of this booklet.



## MEDICINES FOR PARKINSON'S DISEASE

There are several types of medicines that can help relieve some of the symptoms of PD. Overall, the treatments for PD try to bring dopamine levels in the brain back to normal. Doing so may relieve the symptoms of PD. The kinds of medicine used, and the dose you take, may change with time. As the disease progresses, it may also become more difficult to control symptoms. But today many different types of medicines are available, which may extend the length of time symptoms can be controlled.

Here are the types of medicines used to treat PD. Some of these medicines may be taken alone, or in combination with each other:

**Levodopa/carbidopa** works by temporarily increasing the amount of dopamine in the brain.

**Dopamine agonists** mimic the effects of dopamine in the brain.

**COMT inhibitors** are used to extend the action of levodopa. However, they work only if levodopa is taken. They are not useful by themselves.

**MAO-B inhibitors** slow the breakdown of dopamine in the brain. This makes more dopamine available.

**Anticholinergic medicines and amantadine** may be used to help control the tremor that many PD patients experience.

All of these medicines may cause side effects. Talk to your neurologist about what side effects to expect, and what to do if you experience them.





## WHEN A MEDICINE “WEARS OFF”

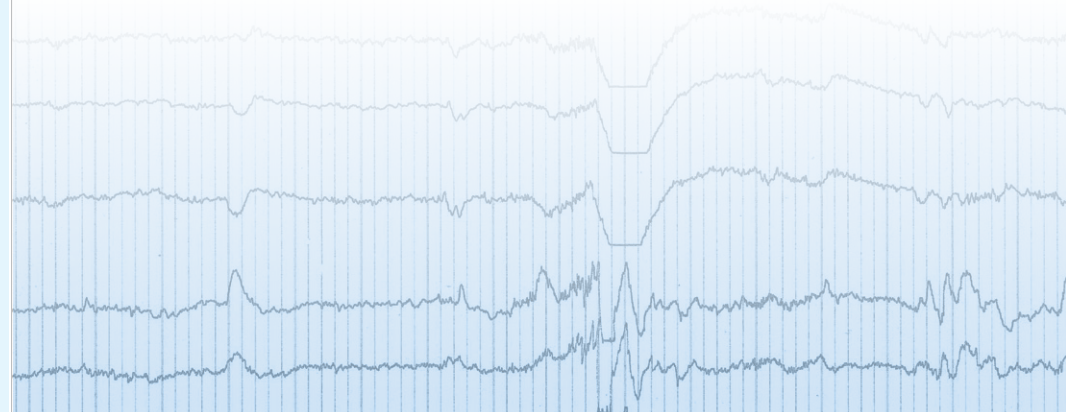
Over time, the way your body responds to a PD medicine may change. Often your medicines work normally to relieve your symptoms (“on” time). You may also, however, have times when the medicine does not work well (“off” time).

Some people who take PD medicines over a long time can develop more “off” time. In addition, some people may experience spasms or uncontrolled muscle movements due to the medicines they are taking. Some side effects may be reduced with other types of medications. Tell your health care professional if you or a loved one are experiencing increasing “off” time or having any side effects.

## DEEP BRAIN STIMULATION

A possible option for people with advanced PD is *deep brain stimulation* (DBS). With DBS, tiny electrodes (wires) are surgically implanted in the brain. The electrodes are connected to a small battery and deliver mild electrical pulses that stimulate the brain.

Although DBS can help treat some of the symptoms of PD, it is not right for all people with advanced PD. Your neurologist or movement disorder specialist can tell you if this treatment might be helpful for you.



## STEPS YOU CAN TAKE

There are many things you can do to help manage your life with PD. How you exercise, what you eat, and how you use your mind can make a difference! Here are some things that have been found to help those with PD:

- **Exercise** – especially swimming, stretching, walking, and exercises to improve your balance. You might also try physical therapy, which is more focused on such things as balance, walking, and strengthening specific muscles.

- **Healthy eating** – a normal diet with plenty of fruits and vegetables will promote overall well-being for PD patients, just as it would for anyone else. It is not necessary to take vitamin supplements, unless suggested by your doctor.

- **Voice therapy** – people with PD sometimes have speech problems. Therapy focused on improving vocal control and voice volume may help you communicate better with others.

- **Alternative approaches** such as acupuncture and massage are widely used by people with PD. Some small studies of acupuncture and massage therapy suggest that such therapies may help relieve symptoms. Other studies have found no benefit. Always be sure to tell your neurologist about any alternative treatments or herbal supplements you may be using.



## CARING FOR A PERSON WITH PD

People with PD often need some help with everyday tasks. They may need more help as the disease gets worse. Spouses and other family members or friends often provide this help. But caring for a person with Parkinson's disease can be tiring or stressful. Caregivers should talk to others about any frustrations they are experiencing. Talk to friends or family members, or join a support group for caregivers. (The Resources section at the back of this booklet can help you find a support group in your area.)

Caregivers need to take care of themselves and make sure their own needs are being met. You don't want to "burn out" or develop your own physical or emotional problems! You need to stay healthy, so you can best care for a loved one with Parkinson's disease.

Watch for signs of depression, confusion, memory problems, or other mental problems in the person with PD. Report any concerns promptly to your loved one's neurologist or doctor.



## CONCLUSION

PD is a serious illness, but there are reasons for hope! People diagnosed today can benefit from medicines that help manage symptoms of PD. New treatments are being discovered as scientists learn more about this complicated disease.

Living with PD is a journey that changes gradually over time. With the help of your neurologist and support from family members and friends, you can live well and thrive with Parkinson's disease.

## RESOURCES

**American Academy of Neurology**  
AAN.com

**American Brain Foundation**  
AmericanBrainFoundation.org

**Neurology Now® Magazine**  
NeurologyNow.com

**Neurology Now® Books**  
“Navigating Life with Parkinson Disease”  
AAN.com/view/PatientBookSeries

**American Parkinson Disease Association**  
apdaparkinson.org

**Michael J. Fox Foundation for Parkinson's Research**  
michaeljfox.org

*To learn how you could help advance Parkinson's research by participating in clinical trials, click on the Fox Trial Finder link*

**National Parkinson Foundation**  
parkinson.org

**Parkinson's Disease Foundation**  
pdf.org

**Parkinson's Action Network**  
parkinsonsaction.org

**Parkinson Alliance**  
parkinsonalliance.org



## Program Presenters

### American Academy of Neurology

The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 26,000 neurologists and neuroscience professionals dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system, such as Parkinson's disease, Alzheimer's disease, multiple sclerosis, epilepsy, and stroke.

For more information visit [AAN.com](http://AAN.com).



### American Brain Foundation

The American Brain Foundation, the foundation of the American Academy of Neurology, is an independent 501(c)(3) organization that funds the most crucial research to cure brain disease, such as Alzheimer's disease, stroke, Parkinson's disease, neuropathy, multiple sclerosis, and epilepsy. Brain disease affects more than 50 million in the United States alone. In moving toward its vision, the American Brain Foundation's goal is to reduce the prevalence of brain disease 50 percent by 2040.

For more information visit [AmericanBrainFoundation.org](http://AmericanBrainFoundation.org).



## Funding Support

### AbbVie

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*Michael J. Fox photos by Mark Seliger*



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Living with PD is a journey that changes gradually over time. With the help of health care professionals and support from family members and friends, you can live well and thrive with Parkinson's disease.

*In this booklet and DVD, you will learn about:*

- Signs and symptoms of PD
- Treatments that may reduce symptoms
- Things you can do to improve your overall health

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