PARKINSON’S DISEASE
A GUIDE FOR PATIENTS AND FAMILIES

Featuring Holly Robinson Peete
DISCLAIMER: This guidebook and DVD program is intended for informational purposes only, with the understanding that no one should rely upon this information as the basis for medical decisions. Anyone requiring medical or other health care should consult a medical or health care professional. Any actions based on the information provided are entirely the responsibility of the user and of any medical or other health care professionals who are involved in such actions.

The collaborator (American Academy of Neurology), the sponsor (Teva Neuroscience), the producers (Conrad Productions and Alan Weiss Productions), the guidebook author (Stephen Braun), the DVD scriptwriter (Deborah Gobble), and the experts who participated in this program (Dr. Stanley Fahn, Dr. William Langston, and Dr. Kathleen Shannon) have made reasonable efforts to include timely and accurate information in this guidebook and DVD. Accordingly, the sponsor, producers, writers, and collaborator make no representations or warranties, express or implied, regarding the accuracy or completeness of the information provided herein and specifically disclaim any liability, express or implied, in connection therewith.

CONTENTS

Introduction ................................................................................... 4
What Causes Parkinson’s Disease? ............................................. 6
How Do I Know If I Have Parkinson’s? ......................................... 8
Movement Disorder Specialists .................................................. 10
Medicines for Parkinson’s Disease ............................................. 12
Deep Brain Stimulation ............................................................... 15
What You Can Do ........................................................................ 16
Caring for a Person with PD ....................................................... 18
Conclusion .................................................................................. 20
Resources ................................................................................... 21
INTRODUCTION

Parkinson’s disease (PD) is a brain disorder. It makes movement difficult and can cause other problems with your muscles. If you or a loved one has been diagnosed with PD, you should know you are not alone! Up to one million people in the US have PD. Every year an additional 40,000 people learn they have this disease.

PD usually appears in adults between the ages of 60 and 65. About one out of 10 people with Parkinson’s disease, however, are 45 or younger. The signs of PD usually come on slowly, and the disease gets worse over time. But PD affects individuals differently. The symptoms a person feels and how quickly the disease progresses can vary a lot from person to person. That’s why it’s important for people to see a neurologist quickly if they or a loved one believes they may have Parkinson’s disease.

Establishing a strong partnership with a healthcare team led by a neurologist is important because PD will persist over a long period of time. A strong partnership will ensure you have access to the many treatments that exist today. While the medical treatments available today cannot cure PD, they can reduce bothersome symptoms and improve your quality of life. Many people with PD live many years with the condition.

This booklet and DVD will help you or a loved one learn more about PD. You will see that there are many things you can do to help both your body and mind cope with this disease. By working closely with your doctor or neurologist, and living a healthy lifestyle, you can live well and thrive with Parkinson’s.

DID YOU KNOW?

Neurologists are medical doctors who specialize in disorders of the brain and nerves. They are the specialists who most often treat people with Parkinson’s disease.
WHAT CAUSES PARKINSON’S DISEASE?

In nine out of every 10 people diagnosed with PD, no clear cause can be determined. Doctors and researchers still have much to learn about this disease! Sometimes, however, PD seems to be genetically inherited. This is most often the case when patients are younger. Most patients with PD have no family members with the disease, but they may still have inherited genes that raised their risk.

No matter what the root cause, the symptoms of PD arise because of a problem in a part of the brain that controls movement. Levels of a brain chemical called dopamine are too low in this brain region. This makes movements jerky and uncontrolled. It can also cause problems such as trembling or shaking. These symptoms may interfere with things you want to do—using a computer, playing tennis, or taking walks, for example.

Most treatments for PD aim to restore dopamine function in the brain to normal levels.

DID YOU KNOW?

Dopamine is a chemical messenger in the brain. It helps you control your muscles. Dopamine also plays a role in mood and behavior.
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. The disease usually comes on slowly and is diagnosed by certain signs and symptoms.

There are four classic symptoms of Parkinson’s disease:
- Tremor when a limb is at rest, most commonly in one hand
- A weak, slow or clumsy limb
- A stiff or aching limb
- Difficulty walking

Examples of other signs of early PD include:
- Small handwriting
- Difficulty with tasks that require fine control, such as buttoning a shirt
- Decreased arm swing when walking

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

Not everyone with PD has all these symptoms. If a person doesn’t have any tremor, diagnosis is more difficult. Some people have symptoms for years before they are properly diagnosed. Patients with PD may also have symptoms that do not involve movement or coordination, such as depressed mood, sleep disturbance, constipation, or limb pain. Unfortunately, all of these signs and symptoms can be caused by other medical conditions. This is why it is best to be diagnosed by a neurologist.
MOVEMENT DISORDER SPECIALISTS

Parkinson’s disease is just one of a large number of conditions called movement disorders. Many kinds of diseases and injuries cause difficulties with moving parts of the body. Movement disorder specialists are neurologists who have studied an additional one to three years in a movement disorder program. They specialize in treating Parkinson’s disease and all other types of movement disorders. You may find it helpful to talk to a movement disorder specialist or undergo treatment with one. (You can find a specialist in your area through some of the groups listed in the Resources section on page 21.)

A movement disorder specialist, either alone or in partnership with another neurologist, can perform the examinations required to make a diagnosis and plan treatment. This may require observing a patient over several months. Medical tests, such as MRI scans, may be used to rule out other potential causes of movement problems. At each visit you will probably be asked a standard set of questions about your symptoms, what kinds of daily living activities you can do, and whether you are feeling side effects of any medications you might be taking. By asking the same questions on each visit, a neurologist can see how you are doing over time.

Once a diagnosis has been made, your neurologist or movement disorder specialist will decide which treatments are most likely to help control your symptoms.

DID YOU KNOW?

Movement disorder specialists are neurologists who have studied an additional one to three years in a movement disorder program.
MEDICINES FOR PARKINSON’S DISEASE

At this time much research is focused on finding treatments that slow or stop PD. The treatments available today have been proven to relieve bothersome symptoms of PD and improve everyday activities. There is no standard or “best” treatment for Parkinson’s disease. People with PD can have a range of symptoms. That means people need to work with their neurologist to find the treatment that is the best “fit” for their needs. Over time, the doctor may increase the dose of medications or add new medications.

Here are the types of medicines currently used to treat PD:

**Levodopa** has been used for more than 30 years to treat PD. It can effectively control symptoms by restoring the supply of dopamine in the brain. Another medicine called **carbidopa** is almost always combined with levodopa in a single pill (carbidopa/levodopa). This extends the effects of levodopa and helps reduce side effects.

**Dopamine agonists** mimic the role of dopamine in the brain. They can be effectively used alone in the early phase. Later, they can be used to prolong the response to levodopa.

**MAO-B inhibitors** slow the breakdown of dopamine in the brain. This makes more dopamine available and helps to improve function. They can be effectively used in the early phase of PD or can be taken with levodopa to extend its effectiveness.

**COMT inhibitors** are another class of medicines that are used to extend the action of levodopa. They work only if levodopa is taken. They are not useful by themselves.

**Anticholinergic medicines** are used to help control the tremor that many PD patients experience.

**Amantadine** is an older medicine with many effects on the nervous system. It can help control tremor and other uncontrolled movements. It can be used alone in the early stages of PD or used later with levodopa.

DEALING WITH MEDICATION SIDE EFFECTS

Over time the response of symptoms to levodopa and other medicines may change, which can result in periods of the day with poor or no response to medication (“off” time). These alternate with periods of improved function (“on” time). Also, people on levodopa can develop involuntary movements, which are called dyskinesias.

Some side effects can be alleviated or reduced with other types of medications. Tell your doctor or neurologist if you or a loved one thinks you may be experiencing these types of side effects.
POSSIBLE ADVERSE EFFECTS OF MEDICATIONS*

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Possible adverse effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levodopa/carbidopa</td>
<td>At start of treatment: nausea, sedation, vomiting, a sudden drop in blood pressure.</td>
</tr>
<tr>
<td></td>
<td>With long-term treatment: delusions, hallucinations, vivid dreams, sleep disturbance, muscle incoordination</td>
</tr>
<tr>
<td>Dopamine agonists</td>
<td>Nausea, sleepiness, vomiting, a sudden drop in blood pressure, confusion, vivid dreams, hallucinations, delusions, impulse-control disorder</td>
</tr>
<tr>
<td>MAO-B inhibitors</td>
<td>Nausea, a sudden drop in blood pressure, possible interactions with certain antidepressants</td>
</tr>
<tr>
<td>COMT inhibitors</td>
<td>Diarrhea, nausea, urine discoloration, daytime sleepiness</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>Constipation, blurry vision, urine retention, confusion, hallucinations</td>
</tr>
<tr>
<td>Amantadine</td>
<td>Nausea, confusion, a sudden drop in blood pressure, insomnia, hallucinations, fluid retention in tissues</td>
</tr>
</tbody>
</table>

*This is not a complete list of possible adverse effects. Check with your doctor for more information.

DEEP BRAIN STIMULATION

The primary non-medicine treatment for Parkinson’s disease is Deep Brain Stimulation (DBS). Tiny electrodes are surgically implanted in the brain. The electrodes are connected to a small, battery-powered control unit implanted under the skin of the upper chest. DBS is only right for 10 to 20 percent of people with PD. Your neurologist can tell you if this treatment might be helpful for you. Any type of brain surgery carries the risk of serious complications. DBS should be performed only if the potential benefits warrant this risk.

When it is successful, DBS helps control tremor, stiffness, and slowness of movement. The technique can extend the length of time your symptoms can be controlled and can reduce the amount of “off” time and uncontrolled muscle movements. Most people treated with DBS continue to take PD medications, but at lower doses.
WHAT YOU CAN DO

There are many steps you can take to improve your quality of life with PD. The choices you make about such things as diet, exercise, and how you use your mind make a difference! Here are some things that have been found to help those with PD:

- **Exercise.** Swimming, stretching, walking, and exercises to improve your balance are especially helpful. You might also try physical therapy, which is more focused on balance, gait, and strengthening specific muscles.

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

- **Healthy eating.** No specific dietary factor is helpful in managing PD, but a normal, healthy diet can promote overall well-being for PD patients just as it would for anyone else. Although some early studies suggested that taking supplements of vitamins A, C, and E might be helpful, later studies found no benefit specific to treating PD.

- **Alternative approaches.** Alternative therapies, such as acupuncture, massage, and nutritional supplements are widely used by patients with PD. Some small studies 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 nutritional supplements you may be using.
CARING FOR A PERSON WITH PD

People with PD often need some help with everyday tasks. They need more help as the disease gets worse. Spouses and other family members often provide this help. Taking care of 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 on page 21 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 that you can best care for a loved one with Parkinson’s disease.

Watch for signs of depression, confusion, memory problems, or other similar problems in the person with PD. Report any concerns promptly to your loved one’s neurologist or doctor. There are many treatments that can help with the kinds of problems that often go along with PD, such as depression, sleep disturbances, mental “fogging,” and hallucinations. The sooner treatment is given, the better chance a person with PD has of retaining a good quality of life.
CONCLUSION

PD is a serious illness, but there is reason to hope! People diagnosed today can expect to be able to control bothersome symptoms. Many treatments can reduce these symptoms and improve your quality of life. 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, it is truly possible to live well and thrive with Parkinson’s.

RESOURCES

American Academy of Neurology Foundation
www.aan.com/go/foundation
www.thebrainmatters.org
800-879-1960

American Parkinson Disease Association
www.apdaparkinson.org
800-223-2732

Michael J. Fox Foundation for Parkinson’s Research
www.michaeljfox.org
800-708-7644

National Parkinson Foundation
www.parkinson.org
800-327-4545

Neurology Now Magazine
www.neurologynow.org
AAN’s patient magazine. Free subscription.

Parkinson’s Action Network
www.parkinsonsaction.org
800-850-4726

Parkinson Alliance
www.parkinsonalliance.org
800-579-8440

Parkinson’s Disease Foundation
www.pdf.org
800-457-6676

Parkinsons Health.com
www.parkinsonshealth.com

The Parkinson’s Institute and Clinical Center
www.thepi.org
800-655-2273

We Move
www.wemove.org
Collaborator

American Academy of Neurology
The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 21,000 neurologists and neuroscience professionals dedicated to promoting the highest quality patient-centered neurologic care and enhancing member career satisfaction. For more information, visit www.aan.com.

American Academy of Neurology Foundation
The American Academy of Neurology Foundation (AAN Foundation) is an independent 501(c)(3) organization affiliated with the American Academy of Neurology (AAN).

The Foundation exists to further the goals of the American Academy of Neurology by supporting education and research in neurology, and is dedicated to improving patient care, quality of life and public understanding of brain and other neurological disorders. For more information about the American Academy of Neurology Foundation, visit www.aan.com/go/foundation.

Sponsor

Teva Neuroscience
Teva Neuroscience is dedicated to the investigation and development of innovative products and services that address the health management needs within the areas of multiple sclerosis, Parkinson’s disease and other neurological disorders. For more information, please visit www.TevaNeuroscience.com.
Credits

Parkinson’s Disease: A Guide for Patients and Families has been made possible through the expertise, time, and efforts of many individuals.

Collaborator

American Academy of Neurology

Contributors to the Video

Stanley Fahn, MD, FAAN
H. Houston Merritt Professor of Neurology
Director, Center for Parkinson’s Disease and Other Movement Disorders
NewYork-Presbyterian/Columbia University Medical Center
New York, NY

J. William Langston, MD
CEO and Scientific Director
The Parkinson’s Institute and Clinical Center
Sunnyvale, CA

Kathleen M. Shannon, MD
Associate Professor, Neurological Sciences
Rush University Medical Center
Rush Medical College
Chicago, IL

Project Manager
Gina Conrad Black
Executive Producer
Conrad & Associates, LLC

Guidebook Author
Stephen Braun
Medical Writer
Amherst, MA

Guidebook Design
Cinda Debbink
Design Partners
www.dgdesignpartners.com

Sponsored by Teva Neuroscience

Special thanks to: Holly Robinson Peete
Parkinson’s disease (PD) is a serious illness, but people diagnosed today can be hopeful that they will be able to control bothersome symptoms. Many treatments can reduce PD symptoms and improve your quality of life. 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, it is truly possible to live well and thrive with Parkinson’s.

In this booklet and DVD, you will learn about:

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

Featuring Holly Robinson Peete