# Parkinson's Disease: YOUR QUESTIONS ANSWERED



#### What is Parkinson's disease (PD)?

PD is a disease that affects a specific type of cell in the brain. These cells normally make a substance called dopamine, which is a "neurotransmitter" that carries messages from one brain cell to another. These messages tell your body to do many things, such as move muscles. When dopamine levels are normal, the brain can help the body move in a normal and coordinated way. In patients with PD, the brain cells that make dopamine begin to die, so dopamine levels drop. With less dopamine in the brain, patients are no longer able to control their movements as well.

# What are the symptoms of PD?

There are two kinds of PD symptoms. "Motor symptoms" affect body movement and muscle control. These are the symptoms that most people think of when PD comes to mind. "Nonmotor symptoms" affect things other than movement and muscles.

The experience of PD is different for every patient. Some people have symptoms from the start, others have few signs at first. Your doctor will ask about your symptoms and keep an eye out for new ones. It is also important for you to tell your doctor about any new problems as you start to have them.

# How did I get PD and who usually gets it?

No one knows how PD develops for any given individual, but the risk of getting PD seems to be affected by genetic factors and by the environment. In the United States, about 1 million people are living with PD, and, each year, more than 50,000 people learn that they have PD. In most cases, PD symptoms start to appear around age 60. Fewer than 10% of patients with PD are diagnosed before age 50.

## Who will be on my care team?

You will likely have help from a number of different healthcare providers, including your primary care physician (PCP), nurses, and a neurologist (a doctor who specializes in diseases of the brain). Some neurologists specialize in caring for people with PD, and a neurologist may help diagnose your PD and plan your treatment. Your PCP, or family doctor, will see you for most of your day-to-day health concerns. This can also include helping you through any problems you may be having with your PD treatment (for example, constipation due to PD and medications) and watching for new symptoms. Your PCP and neurologist will work together to make any changes to your treatment. Your PCP will also continue to see you for other health issues that are

MOTOR SYMPTOMS OF PD					
SYMPTOM	MEDICAL TERM		DESCRIPTION		
Shaking	Tremor		Usually starts on one side of the body and may affect only one body part, like the hand or foot. As PD gets worse, the shaking can affect other parts of the body and may be more noticeable with stress. Shaking often disappears during sleep or when the affected arm or leg is moving.		
Slow Movement	Bradykinesia		As movement slows, it may take longer to do common tasks like taking a shower and getting dressed.		
Stiff Arms and Legs	Rigidity		When muscles are tense on a regular basis, it can lead to stiff limbs and problems with moving freely. Affected muscles can ache or be sore.		
Other examples: changes in walking, posture, speech, and handwriting; loss of balance; increased risk of falls.					
NONMOTOR SYMPTOMS OF PD					
SYMPTOM TYPE		EXAMPLES			
Psychiatric/Neurologic		Depression, anxiety, seeing things that are not there, impulse problems			
Cognitive		Confusion, dementia, memory problems, difficulty thinking, some visual problems			
Autonomic		Constipation, nausea, urinary problems, sweating too much, sexual problems			
Sleep Related		Broken-up sleep, insomnia, daytime sleepiness			

not related to PD. Other healthcare professionals who may be part of your care team include:

- **Physical therapists.** A physical therapist can help you come up with an exercise plan that works with and helps your PD symptoms.
- Occupational therapists. Occupational therapists can visit your home and offer tips for some simple changes, such as the location of railings, special toilet seats, and special kitchen utensils, that can make living with PD easier and safer.
- **Speech therapists.** Speech therapists can help if speech problems start to develop. They can also help patients who have trouble swallowing. There are special exercises they can suggest that can help build up the muscles involved in these tasks.

#### How is PD treated?

In general, there are two approaches to drug therapy in PD. The first is to use medications that improve the way dopamine works in the brain. Different drugs can be used to help the body make more dopamine, to act like dopamine in the body, or to slow the loss of dopamine. These medications are mainly used to manage the motor symptoms of PD. In some cases, two agents can be used together for more benefit.

The second approach to drug therapy involves medications that treat the individual symptoms of PD. Many of the nonmotor symptoms of PD are treated this way. For example, depression in patients with PD is treated with an antidepressant and excessive sleepiness can be treated with medication that helps patients stay awake.

# Can PD be treated with surgery?

Drug therapy can help most patients with their PD symptoms. For some patients, however, at some point drug therapy may cause almost as many side effects as benefits. For these patients, there are safe and effective surgical treatments for PD that can be considered.

Deep brain stimulation (DBS) is a type of surgery that places an electrode into one of three areas of the brain. The electrode is controlled by a device that is placed under the skin in the chest, similar to a heart pacemaker. The device sends electrical pulses to the electrode in the brain, blocking the impulses that cause tremors and other PD symptoms.

#### What treatment is best for me?

Your doctors will discuss your options for PD treatment. Together, you will decide on a treatment plan that works best for you. The best treatment depends on many factors, such as:

- Your age
- Your symptoms
- Your general health
- Your preference
- The expected benefit
- The risk of side effects
- Your response to past treatment(s)

When you start or change any medications, your doctor will talk about what you can expect with the treatment, including how you will know if it's working and how long it may take to start working.

# What are the risks and side effects of PD treatment?

Different treatments have different side effects. Your doctor can talk to you about the side effects that go along with each. It is important to have a plan for managing side effects. Family members and other caregivers should also understand the risk of side effects. Most patients do not have major side effects. The long list of possible side effects can be scary and may make you want to avoid taking medications until your symptoms have gotten really bad; your doctor can talk through this with you if you start having such concerns.

COMMON DRUG THERAPIES FOR PD					
TYPE OF DRUG	BRAND NAME (GENERIC)	HOW IT WORKS			
COMT Inhibitors	Comtan (entacapone); Tasmar (tolcapone); Stalevo (entacapone/levodopa/carbidopa)	Given with levodopa/carbidopa to keep dopamine from being destroyed			
Dopaminergic Agents	Sinemet, Sinemet CR, Parcopa (levodopa/carbidopa)	Helps to make more dopamine in the brain			
Dopamine Agonists	Parlodel (bromocriptine); Mirapex (pramipexole); Requip (ropinirole); Neupro (rotigotine)	Acts in the brain the same way that dopamine does			
MAO-B Inhibitors	Azilect (rasagiline); Eldepryl, Zelapar (selegiline)	Keeps dopamine from being destroyed			
Multiple Actions	Symmetrel (amantadine)	Increases dopamine release			

#### Will treatment cure me?

Researchers are hoping to find a cure, but right now there is no known cure for PD. The current goal of treatment is to identify and control symptoms. By focusing on that goal, most patients with PD can live enjoyable and rewarding lives.

# What other things can I do to improve my quality of life with PD?

In addition to taking medications for PD, you should take part in other healthful activities. All patients with PD should practice good sleep habits and eat a healthy diet. Other habits that can improve your quality of life include exercising and staying socially active.

Exercise is important because PD affects your ability to control your muscles. Exercise can improve your strength, flexibility, and ability to move. It can also help your balance and gait (the manner in which you walk). Exercise can also put you in a better mood and make you feel better. Some research indicates that physical exercise may improve memory and thinking. Some things to keep in mind:

- Check with your doctor before starting an exercise program. Ask if there are certain exercises that you should/should not try.
- If your doctor says that you can exercise, start slowly.
- Choose an activity or hobby that you will enjoy and want to keep doing, such as walking, swimming, gardening, yoga, dancing, Tai Chi, or water aerobics.

Interacting with family, friends, and others in the community is important for your psychological and emotional health. As the symptoms of PD appear, some patients may find it challenging to keep up with social interactions. The physical symptoms of PD can change a person's voice and facial expressions in ways that others might not understand. Reduced mobility, changes in mood, and other symptoms can also cause problems with normal social interaction.

Steps for improving social interaction include:

- Find a PD support group that is appropriate for you; for example, some groups focus on young onset or other aspects of PD. In addition to learning more about PD, you and your family members can benefit from the social aspect of the group.
- Ask your doctor for a referral to a social worker for information about supportive services, such as community senior centers and transportation services.

## How can I find support groups in my area?

Several groups are available to help you find PD support in your area. These include:

- The Parkinson's Disease Foundation (PDF) keeps a list of PD support groups; call them at 1-800-457-6676 to find a support group in your area.
- The National Parkinson Foundation (NPF) has a searchable online map of local NPF chapters (www.parkinson.org/Search-Pages/Chapter-Locator); you can also call them at 1-800-4PD-INFO (1-800-473-4636) for support groups and other resources in your area.

PD DRUGS AND THEIR COMMON SIDE EFFECTS				
TYPE OF DRUG	BRAND NAME (GENERIC)	SIDE EFFECTS		
COMT Inhibitors	Comtan (entacapone); Tasmar (tolcapone); Stalevo (entacapone/levodopa/ carbidopa)	<ul> <li>May exaggerate some levodopa-related side effects</li> <li>Confusion, hallucinations, changes in urine color, diarrhea</li> </ul>		
Dopaminergic Agents	Sinemet, Sinemet CR, Parcopa (levodopa/carbidopa)	<ul> <li>Can cause your muscles to move on their own (with long-term use); these movements are called dyskinesias</li> <li>Nausea, sleepiness, hallucinations, vivid dreams, illusions, low blood pressure</li> </ul>		
Dopamine Agonists	Parlodel (bromocriptine); Mirapex (pramipexole); Requip (ropinirole); Neupro (rotigotine)	<ul> <li>Nausea, vomiting, dizziness, light-headedness, confusion, hallucinations, sudden sleepiness</li> <li>May cause or worsen impulse-control problems</li> </ul>		
MAO-B Inhibitors	Azilect (rasagiline); Eldepryl, Zelapar (selegiline)	<ul> <li>Rasagiline: flu syndrome, joint pain, depression, indigestion, risk of adverse food/drug interactions</li> <li>Selegiline: dry mouth, insomnia, nausea, dizziness, headache, changes in heart rate/rhythm</li> </ul>		
Multiple Actions	Symmetrel (amantadine)	Hallucinations, confusion, dizziness, nausea, vomiting, anxiety, insomnia, nervousness, swelling, discoloration in the legs		

#### What about clinical trials?

Many new treatments for PD are being studied in clinical trials. Types of treatments being looked at include:

- Medications to slow the progression of PD
- Medications to help with symptoms of PD
- Surgeries to test new devices for treating PD
- Other therapies, including exercise, physical therapy, and behavioral therapy

In many cases, you can participate in a clinical trial while continuing your regular PD treatment. If you are interested, ask your doctor if there are any clinical trials that might be an option for you. Participating in a clinical trial can improve your own care. It can also help with the development of new treatments that may help others one day. The decision to join a clinical trial is a highly personal one. Good communication with your doctors is a key factor in such a decision.

#### Where can I find resources about PD?

- American Parkinson Disease Association (www.apdaparkinson.org/)
- National Parkinson Foundation (www.parkinson.org)
- Parkinson's Action Network (www.parkinsonsaction.org/)
- Parkinson's Disease Foundation (www.pdf.org/)
- The Michael J. Fox Foundation for Parkinson's Research (www.michaeljfox.org)

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