Understanding Parkinson's Parkinson's FAQ

What is Parkinson's disease?

Parkinson's disease (PD) is a chronic and progressive movement disorder that involves the malfunction and death of vital nerve cells in the brain, called neurons. Some of these dying neurons produce dopamine, a chemical that sends messages to the part of the brain that controls movement and coordination. As Parkinson's progresses, the amount of dopamine produced in the brain decreases, leaving a person unable to control movement normally.

2 What are the symptoms of Parkinson's?

The four key motor symptoms of Parkinson's disease are tremor of the hands, arms, legs or jaw; muscle rigidity or stiffness of the limbs and trunk; slowness of movement (bradykinesia); and postural instability (impaired balance and coordination). Other common symptoms may include pain; dementia or confusion; fatigue; sleep disturbances; depression; constipation; cognitive changes; fear or anxiety; and urinary problems. All of these symptoms can vary from person to person.

3 How many people have Parkinson's?

An estimated seven to 10 million people worldwide live with Parkinson's disease. In the United States, as many as one million individuals live with PD, which is more than the combined number of people diagnosed with multiple sclerosis, muscular dystrophy and Lou Gehrig's disease. Approximately 60,000 Americans are diagnosed with Parkinson's disease each year, and this number does not reflect the thousands of cases that go undetected. Incidence of Parkinson's increases with age, but an estimated four percent of people with PD are diagnosed before the age of 50. Statistics have shown that men are slightly more likely to have Parkinson's disease than women.

4 What causes Parkinson's?

As is the case with many neurological disorders, the cause of Parkinson's disease is not known. However, scientists and researchers are working diligently to uncover the possible cause(s), including genetic and environmental factors, of Parkinson's disease.

5 Is Parkinson's inherited?

Although the vast majority of Parkinson's cases are not directly inherited, researchers have discovered several genes that can cause the disease in a small number of families. Research on these rare genetic forms is contributing greatly to advancing the understanding of all forms of Parkinson's. In large population studies, researchers have found that people with an affected first-degree relative, such as a parent or sibling, have a four to nine percent higher chance of developing PD, as compared to the general population. This means that if a person's parent has PD, his or her chances of developing the disease are slightly higher than the risk among the general population.

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6 How is Parkinson's diagnosed?

There is no standard test to conclusively show if a person has Parkinson's disease. Because of this, it can often be difficult to diagnose. The disease should be diagnosed by a neurologist with experience and training in assessing and treating Parkinson's, ideally a movement disorder specialist. Physicians rely on a neurological examination and the individual's descriptions of symptoms to determine whether he or she has Parkinson's. A neurologist may order several tests to rule out other conditions before diagnosing a person with Parkinson's disease.

7 How do you treat Parkinson's?

Although there is currently no cure for Parkinson's, there are treatment options available such as medication and surgery to manage its symptoms. Levodopa is the most widely prescribed Parkinson's medication, and people often take several other medications to manage the disease. Surgical options, such as deep brain stimulation, may help alleviate a person's Parkinson's symptoms if and when they stop responding favorably to medication. However, surgery is only effective for a small group of people with Parkinson's and is only recommended if an individual meets specific criteria.

8 Can people die from Parkinson's?

Parkinson's disease is a progressive disorder, and although it is not considered to be a fatal disease, symptoms do worsen over time and make life difficult. People with Parkinson's experience a significantly decreased quality of life and are often unable to perform daily movement functions, such as getting out of bed unaided and driving. Most individuals are eventually forced to stop working due to the unavoidable progression of disabling symptoms. In some cases, people have died from Parkinson's-related complications, such as pneumonia.

9 What is the cost of Parkinson's?

The amount of money that the United States and individuals spend each year on Parkinson's disease is staggering. The combined direct and indirect cost of Parkinson's disease, including treatment, social security payments and lost income from inability to work, is estimated to be nearly \$25 billion per year in the United States alone. Medication costs for an individual person with Parkinson's average \$2,500 a year, and therapeutic surgery can cost up to \$100,000 per individual.

10 What can be done to find a cure for Parkinson's?

Over the last decade, the National Institutes of Health (NIH) have devoted significant resources to making substantial advances in neurosciences, in lab and animal studies as well as clinical trials. However, a potential crisis in Parkinson's clinical research is looming because the number of people volunteering to participate in clinical trials is not keeping up with the growth of available trials. To find out about clinical trials and how to participate, please visit <u>www.PDtrials.org</u>, a website created by the *PDtrials* coalition to provide a listing of Parkinson's clinical trials that are open for enrollment. To learn more about clinical research advocacy, visit <u>www.pdf.org/en/clinical trial inv</u>.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice.

This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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