

The Parkinson's Disease Foundation

The Parkinson's Disease Foundation (PDF) is a leading national presence in Parkinson's disease research, patient education, and advocacy for increased federal funding. PDF is working for the nearly one million people in the U.S. living with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and one-on-one advice services.

Since our founding in 1957, PDF has awarded over \$50 million to fund scientific research into the causes of Parkinson's.

Our services to the Parkinson's community include:

- Provision of printed and audiovisual educational materials to support patients, families and caregivers who live with Parkinson's.
- A support service run by trained health professionals and medical staff to answer questions from patients, caregivers, families and the community on any aspect of Parkinson's disease through our telephone advice line, (800) 457-6676 and web-service, "Ask the Expert".

PDF is a tax-exempt, charitable organization with offices in New York and Chicago.

For further information about our services or to support our work, please see our website at www.pdf.org or write to us at the address below.



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PARKINSON'S DISEASE



A GUIDE FOR PATIENTS

FOURTH EDITION

The Forty Most-Frequently-Asked Questions About Parkinson's Disease

Introduction

People with Parkinson's disease are looking for answers. This pamphlet is our list of the questions most frequently asked by people with Parkinson's disease, their families, and caregivers. Some of the questions are practical and have simple answers. Others reflect larger issues that researchers are investigating, so the answers are still evolving. The booklet is divided into five sections for easy referencing:

- Understanding Parkinson's disease
- Treating Parkinson's disease
- Common problems in Parkinson's disease
- Daily living with Parkinson's disease
- Parkinson's disease research – the future

We hope our answers provide helpful information that enables patients to understand and cope with their symptoms. If you would like more information about PD, please contact us at the Parkinson's Disease Foundation. Your questions are welcome!

This publication was written and edited with the help of the following outstanding movement disorder specialists at Columbia University Medical Center. PDF thanks them for devoting their time and expertise to create this publication and for their commitment to the Parkinson's community.



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UNDERSTANDING PARKINSON'S DISEASE

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1. What are the signs of Parkinson's disease?

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PD was originally described in 1817 by James Parkinson in his *Essay on the Shaking Palsy*. The diagnosis of PD depends upon the presence of one or more of the four cardinal symptoms of the disorder:

Resting tremor In the early stages of the disease, about 70 percent of people experience a slight tremor in the hand or foot on one side of the body. Less common is a tremor in the jaw or face. The tremor of PD is a regular to-and-fro oscillating movement at about 4 beats per second. Because tremor usually appears when the muscles are relaxed, it is called "resting" tremor. The resting tremor of PD typically occurs in an arm resting in the lap, or on an armrest, or when it is dangling by one's side when standing or walking. The tremor of PD can increase under stress or excitement, sometimes attracting unwanted notice. Many patients are aware that their resting tremor will diminish or resolve completely when they bring the body part into active use. By keeping a hand busy, for example, a patient can prevent the tremor that occurs when the hand is resting. Although tremor is the most noticeable outward sign of the disease, not everyone with PD develops tremor.

Bradykinesia Bradykinesia means "slow movement". People with Parkinson's have slow movements and a diminished range of movement. Due to bradykinesia, a person may have difficulty sustaining repetitive movements, such as brushing the teeth. The absolute amount of movement decreases in PD, giving patients an unnaturally still appearance. A lack of spontaneous blinking and movement in the face can give a serious or mask-like expression. As a result of bradykinesia, people with Parkinson's may begin to walk with short, shuffling steps. People with Parkinson's can move quickly when

they have to and show a full emotional range of facial expression. But, due to bradykinesia, spontaneous movement does not come naturally.

Rigidity Normally, muscles contract when they move and relax when they are at rest. A limb at rest should be smoothly pliable. In patients with muscular rigidity, the tone of an affected limb is stiff. When tested by a neurologist, a patient with rigidity shows resistance to passive movement that has a ratchety “cogwheeling” quality.

Postural instability Postural instability leads to poor balance. If the balance is slightly disturbed, a patient may not be able to recover, and instead topple over. Many people with PD have a tendency to fall backwards after a slight push or bump. Others tend to fall when turning or attempting to pivot. Neurologists test postural stability by using the “pull test.” During this test the neurologist gives a moderately forceful backwards tug on the standing patient, and observes how well he can recover. The normal response is a quick corrective backwards step to prevent a fall. Of course, if the patient has postural instability, the neurologist is right there to catch him.

In addition to the four cardinal signs of PD, there are other clinical signs of the illness. “Freezing” of gait is a tendency for the feet to stick to the floor, and hesitate during the act of stepping. This problem can lead to a forward fall. If the feet are stuck standing still and the body is moving forward, the person will be propelled to the ground.

Other symptoms and signs include a softening of the voice, rapid or stuttering speech, an excess of saliva, shrinkage in the size of handwriting, a flexed or stooped posture, constipation, bladder problems and depression. All of these problems are discussed in this booklet.

It is important to realize that not every person with PD develops all signs or symptoms of the disorder. Some patients experience tremor as the primary, or exclusive, symptom, while others may lack tremor but experience a balance problem instead.

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2. How is Parkinson’s disease diagnosed?

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PD is diagnosed in the old-fashioned way: by a careful neurological history and examination, performed by an experienced practitioner. There are no simple diagnostic tests for PD, so the diagnosis rests on the clinical information provided by the patient and the findings on exam. Very mild cases of PD can be hard to identify, even by an experienced neurologist. In addition, there are many neurological conditions that mimic the appearance of PD, so a careful distinction between the various causes of “parkinsonism” is needed. For this reason, a person with symptoms resembling those of PD should consult a neurologist with special training in the recognition and treatment of the disease.

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3. How important are tests in diagnosing Parkinson’s disease?

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There is no diagnostic test for PD. Researchers have long sought to develop an accurate “biological marker” of PD, whether a blood test, an electrophysiological test, or a neuroimaging study, to diagnose PD and follow its course. To date, the best objective testing for PD consists of specialized brain scanning techniques that can measure the dopamine system and brain metabolism. But these tests are performed only in specialized imaging centers and are exceedingly expensive.

From a practical perspective, the only useful diagnostic evaluation for PD is testing for diseases that mimic PD. These tests may include a blood test for copper metabolism, genetic testing if appropriate, and a brain magnetic resonance image (MRI) to rule out the presence of multiple small strokes or hydrocephalus. Typically, in PD, the neuroimaging studies, whether computerized tomography (CT) or MRI, are normal. Some physicians routinely order nerve conduction studies, electromyography (EMG), or an electroencephalogram (EEG), but these are expensive and unnecessary in the diagnosis of PD.

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4. What causes Parkinson's disease?

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Why an individual develops PD remains unclear. The causes of PD likely include a combination of both genetic and environmental factors, and may vary from person to person. In some patients, genetic factors may play a role; in others, an injury, illness, aging, environmental toxin or other event may play a role. To date, despite decades of intensive study, the cause of PD remains unknown. However, scientists have identified factors that contribute to PD in some patients. There is a 2-4 percent risk among people over age 60, compared with 1-2 percent in the general population.

Genetic factors About 15-25 percent of PD patients report having a relative with Parkinson's. In large epidemiological studies, researchers have found a 2-to-3 fold increased risk of developing PD in people with an affected first-degree relative, such as a parent or a sibling, as compared to the general population. This means that if your parent has PD, your chances of developing the disease are higher than the risk in the general population, although this risk remains small.

The vast majority of PD cases are not directly inherited. In a small number of families, however, researchers have discovered several genes that can cause the disease. Some of these genes involve proteins that play a role in dopamine cell functions. For families with inherited PD, genetic counseling is available. Genetic aspects of PD are the subject of intense research.

Environmental factors Some scientists have suggested that Parkinson's disease may result from exposure to an environmental toxin or injury. It has long been known that serious or recurrent head injury, such as happens to boxers, can produce a form of parkinsonism. Epidemiological research has identified several factors that may be linked to PD, including rural living, well water, herbicide use and exposure to pesticides. A synthetic narcotic agent called MPTP can cause immediate and permanent parkinsonism if injected.

Whenever an association between an environmental factor and PD is observed, scientists are

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5. What happens to brain cells in Parkinson's disease?

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In PD, a population of cells residing in a motor control area of the brain called the substantia nigra begins to deplete. These cells are responsible for manufacturing the chemical dopamine, and for transmitting it to adjacent brain structures, the caudate and putamen. The result of a declining dopamine cell population is a dopamine shortage in this part of the brain. For most patients, this process leads to the motor impairments of PD: tremor, stiffness and slowness of movement. In some advanced cases of PD, the disease appears to extend beyond the dopamine motor system, and involve other brain systems, causing emotional and cognitive symptoms.

When scientists examine the dying process of dopamine cells, they find a pattern of visible changes in the cell shape and organization. The pattern of cell death in PD is unique to humans, and there is no other animal that spontaneously develops this condition. The cell death process appears to involve a cascade of biochemical reactions inside the cells. The trigger that starts the cell death process in PD is unknown, and may differ from patient to patient. Some patients appear to carry a gene defect that allows the development of PD. Other individuals may be exposed to an environmental toxin or injury. Many believe that by understanding the sequence of events that leads to the loss of dopamine cells, scientists will be able to develop treatments to halt or reverse the disease.

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6. I've heard of drug-induced Parkinson's disease. What is this and what causes it? Is it permanent or reversible?

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Drug-induced parkinsonism is one of the mimics of PD. Certain drugs can produce symptoms and signs that are clinically indistinguishable from classic Parkinson's disease, including resting tremor, rigidity, slowness to initiate or

carry out movement and problems with balance. Drug-induced parkinsonism is caused by drugs that block the effect of dopamine in the brain. Fortunately, when these drugs are stopped, the dopamine system returns to normal and all of the features of parkinsonism reverse.

Drugs that can cause parkinsonism include neuroleptic tranquilizers, sometimes used to control hallucinations or agitation, or to induce sleep. Examples of this class of drug include chlorpromazine (Thorazine), haloperidol (Haldol), fluphenazine (Prolixin), pimozide (Orap), risperidone (Risperdal) and olanzapine (Zyprexa). A drug for nausea, metoclopramide (Reglan), can block dopamine in the brain and cause parkinsonism. Reserpine, a drug once widely used to treat high blood pressure, can deplete brain dopamine and cause parkinsonism. Certain cardiac medications, including amiodarone and calcium channel blockers, may induce parkinsonism. The antidepressant amoxapine has a similar effect.

If a person who already has PD takes one of these drugs, the symptoms of parkinsonism may worsen. Because so many drugs have an impact on the dopamine system, it is important to list all of your medications when you visit your neurologist.

Q 7. Can a bad fall, accident or shock cause Parkinson's disease?

A Many people with PD state that their symptoms first became apparent after a severe shock, such as a head injury, a medical illness, an operation, or severe emotional stress. Because PD is a slow degeneration of brain cells occurring over many years before the first symptom appears, it seems unlikely that any single stress is responsible for the disease. It seems more likely that an individual who was in the process of developing PD only became aware of the symptoms after a severe stress.

Scientists are learning that PD results from a cascade of biological reactions that play a role in brain cell integrity and repair. It is believed that the gradual failure of brain cell repair mecha-

nisms can make an individual vulnerable to injury, such as a head trauma. Indeed, it has long been known that repeated head trauma can cause a state of parkinsonism and dementia, sometimes seen in boxers.

Q 8. If I have Parkinson's disease symptoms on only one side, will they ever show up on the other side as well?

A By definition, PD is a progressive disease. Some people with Parkinson's only have symptoms on one side of the body for many years, but eventually the symptoms start on the other side. Because PD is often an asymmetrical condition, even when it spreads to the other side, the symptoms do not necessarily reach equal severity.

Q 9. Does daily stress worsen PD symptoms?

A What is stress? Stress means different things to different people. One definition of stress is a situation or demand that poses a physical or psychological challenge. Stress can be good or bad. An injury, a conflict, a medical illness, an operation, a physical discomfort, and sleep deprivation are examples of negative stresses. Important life occasions or social situations are examples of positive stresses that may also have an impact on PD. Stress is not the cause of PD but stress of any kind can briefly worsen PD symptoms. It is important to realize that the increase in symptoms experienced during stressful situations is temporary and will resolve after the stress is relieved.



TREATING PARKINSON'S DISEASE

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10. How do I find a physician who is knowledgeable about Parkinson's disease?

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Finding the right physician is one of the most important steps a patient must accomplish. Individuals with PD have a special need for physicians who are knowledgeable, compassionate, willing to listen and available to help during times of crisis. The ideal physician for a patient with PD is a neurologist with training and experience in diagnosing and treating PD. Because there are so many new developments in the Parkinson's field, it is important that your physician be up-to-date and aware of new therapies.

Finding the right physician may take time. Try talking to other people with PD (for example, individuals you might meet at a support group) and asking if they can recommend a physician with whom they have had a good experience. Another way to find a physician is through local medical societies or individual healthcare plans. In the current climate of health maintenance organizations (HMOs), one doctor may be assigned all PD patients in a group practice but this is not always an indication of expertise or special training.

In our opinion, patients with PD are well served by a multi-disciplinary approach that provides not only the expertise of a Parkinson's specialist, but also the help of physical therapists, speech therapists, nutritionists, and social workers. Some patients also require medical consultants in other areas such as internal medicine, psychiatry and neurosurgery.

Across the country are many specialized centers that can provide comprehensive care for individuals with PD. The Parkinson's Disease Foundation maintains a list of specialists in PD. If you need to find a PD expert in your area, you are welcome to call us at (800) 457-6676, or send an email to info@pdf.org.

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11. How often should I see my physician?

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Most people with PD are advised to see their physicians every three to six months, especially if they are taking anti-PD medications. If you are having problems with your condition or its treatment, more frequent visits may be warranted. Some patients remain in regular contact with their physicians by telephone, letter or, increasingly, by e-mail. In the era of modern medicine, when many patients have multiple specialists, it is important that all of these specialists communicate regularly with each other!

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12. What is the best treatment for Parkinson's disease?

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There is no single answer to this question. The treatment of PD is a much larger issue than can be discussed here. But the principles of treatment can be described.

So far, there is no cure for PD. For most patients, the goal of treatment is to reduce the symptoms of PD to allow the individual to function as normally as possible, and with as few side-effects as possible. Not every patient has the same symptoms, so the treatment needs to be tailored for each individual.

In recent years, many new medicines have appeared on the market, and many more are under study. To patients and physicians alike, the array of medications for PD is staggering. The specific choice of therapy depends on the symptoms, degree of disability, personal and occupational responsibilities, and the presence of adverse effects.

The most effective medications for PD are drugs that help the dopamine system. Dopamine agonists, like bromocriptine (Parlodel), pergolide (Permax), pramipexole (Mirapex), and ropinirole (Requip), stimulate dopamine receptors. The most potent medication for PD is levodopa, usually offered in a combined carbidopa-levodopa formulation named Sinemet or as a carbidopa-levodopa-entacapone formulation called Stalevo. Levodopa is an amino acid that is converted into dopamine by an enzyme in the brain. As a class, all dopamine drugs may cause nausea

and lightheadedness due to low blood pressure, so it is important to be careful when starting a new agent. Another class of medications, catechol-o-methyl transferase (COMT) inhibitors, such as entacapone (Comtan), or a combined carbidopa-levodopa-entacapone formulation (Stalevo), are useful in boosting and prolonging the effect of levodopa.

In general, mild PD that consists of a tremor at rest can often be treated initially with anticholinergic agents. Anticholinergic agents work on brain circuits that use acetylcholine, another neurotransmitter that plays a role in the motor system. Amantadine is a mild medication that has dopaminergic and anticholinergic properties, and is useful in early PD.

For more severe symptoms, dopaminergic medication, whether a dopamine agonist or levodopa, is prescribed. Some patients take multiple medications for their PD throughout the day. It is important to note that the medications for PD do not stop the disease from progressing, so many patients require more medication as time passes. But the goal of treatment—to keep a person functioning at a high level—remains the same. At all stages of PD, important nonpharmacologic interventions, including exercise, nutrition, education and support, are very important.

For detailed information on how the medications for PD work, as well as their potential side-effects and interactions, visit www.pdf.org or request your copy of PDF's medication brochure by calling (800) 457-6676. This brochure includes an up-to-date table of Parkinson's drugs, tips for administering drugs, hints to help you save money, an overview of surgical procedures and a glimpse into the pipeline of future medications.

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13. I've heard that levodopa should be avoided as long as possible. Is this true?

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Forty years after its discovery, levodopa remains the most effective medication for PD, and the gold standard by which all treatments for PD are measured. But despite four decades of clinical experience, involving millions of patients worldwide, important questions about the role of levodopa and its effect on PD remain.

Currently, about 70–80 percent of all treated PD patients are on levodopa therapy. The biggest issue is when to introduce levodopa in the treatment of PD. Should levodopa be given during the early stage of disease, or should it be withheld as long as possible?

Some experts advocate early treatment with levodopa because the drug is extremely effective in early-stage PD. They argue that levodopa has little effect on the underlying disease, so there is no reason to believe that it will aggravate PD or accelerate the development of complications.

Other experts argue that levodopa treatment frequently results in wearing-off spells and involuntary writhing movements, termed dyskinesias, so it is desirable to avoid exposure to the drug as long as possible. These experts are concerned about the theoretical possibility that levodopa might accelerate an oxidation process that occurs in dopamine cells, leading to worsening PD. Despite a lively debate in the medical literature, neither viewpoint has been proven.

The argument that levodopa should be postponed because it only works for a limited period of time is not valid. In fact, it is more likely to be effective longer if introduced earlier. But earlier treatment with levodopa tends to produce earlier development of wearing-off fluctuations and dyskinesias.

A reasonable therapeutic compromise, adopted by many experts, is to treat early stage PD using milder medications, such as amantadine or dopamine agonists, and adding levodopa when required for more symptom control. But in patients older than 70 years, dopamine agonists are associated with frequent hallucinations and sedation, so using levodopa as a first-line drug is preferable.

Many patients take a combination of levodopa, agonists, amantadine and other agents, depending on their symptoms. Unfortunately, because the brain's dopamine store progressively depletes in PD, greater dependence on medication over time is anticipated. Patients may reduce their medications at any time but the usual result is a return of PD symptoms.

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14. What about surgical procedures for PD?

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Surgery for PD was first developed in the 1930s when innovative surgeons created tiny lesions within the deep structures of the brain to interrupt tremor. Over many decades, through advances in surgical procedures and neuroimaging techniques, modern surgical approaches have become as effective as medication at relieving some PD symptoms.

The state-of-the-art surgical procedure for PD is deep brain stimulation, a technique that involves placing a tiny electrode deep into the brain. The electrode is connected by a subcutaneous (under the skin) wire to a battery pack implanted beneath the collarbone, like a pacemaker. This technique was first approved by the U.S. Food and Drug Administration in 1997, and has been used successfully in thousands of patients worldwide.

Deep brain stimulation targets different parts of the brain, including the subthalamic nucleus, globus pallidus and thalamus, all sites that are useful in the treatment of PD. The choice of target depends upon a patient's symptoms. For patients with symptoms on both sides of the body, the surgery must be performed on both sides of the brain. After the surgery is accomplished, patients must return to the medical center at regular intervals for programming their implanted devices.

Like medication treatment, surgery for PD is not a cure. But it is very effective in suppressing symptoms of PD, especially tremor. When treated using subthalamic nucleus stimulation or globus pallidus stimulation, patients with advanced PD may experience a 30–80 percent reduction in their symptoms, including tremor, bradykinesia and rigidity. Wearing-off spells and dyskinesias can also be dramatically reduced. Some patients can decrease their medication intake by 50 percent or more. Unfortunately, surgery for PD does not help balance or gait freezing, and has limited effects on speech or posture—all symptoms that may get worse as the disease progresses. For this reason, some patients who undergo surgery are not happy with the results.

Not every patient with PD is a good candidate for surgery. The ideal candidate is responsive to levodopa but has reached a stage that brings wearing off spells or dyskinesias. The individual should have no cognitive impairment and be in good general health. An effective support system of family or friends is essential to help the patient cope with the emotional demands of the surgery. Patients with forms of parkinsonism that respond poorly to levodopa or who experience cognitive or emotional impairment, will not benefit from surgery.

Surgery for PD is best performed at a center with established expertise in these advanced techniques. The ideal center is one that has advanced intra-operative physiological mapping capacity, neurosurgeons who are specially trained in stereotactic surgery, and a dedicated team of clinical personnel who are available for programming the deep brain stimulator.

For more information on surgery for PD, please contact the Parkinson's Disease Foundation and obtain a copy of our comprehensive booklet "Surgery for Parkinson's Disease".

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15. What is neuroprotection?

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Neuroprotection is the term used to describe treatment that may slow down, stop or reverse the progression of PD. Researchers are attempting to develop neuroprotective agents for PD, as well as other neurodegenerative conditions, such as Alzheimer's disease and amyotrophic lateral sclerosis (ALS). But unfortunately, no therapy currently offers effective neuroprotection.

The antioxidant selegiline is often used as an initial therapy in early PD, despite the lack of strong evidence that this medication has an important neuroprotective effect. Many patients use over-the-counter antioxidant vitamins, such as vitamin E, vitamin C or coenzyme Q10, with the goal of slowing PD progression.

As scientists learn more about the cascade of biological reactions leading to dopamine cell death, it is hoped that specific cell death inhibitors will become available as neuroprotective agents. In addition, research on nerve growth factors, especially one called glial cell line-derived neurotrophic factor (GDNF), shows promise as a neuroprotective therapy for PD.

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16. What forms of physical therapy are available for Parkinson's disease?

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Physical and occupational therapies can be very beneficial for people with PD. Physical therapists concentrate on walking, balance and large body movements. Physical therapy can assist people with PD to identify the safest ways of moving, and help them develop daily exercise regimes to keep them mobile.

Occupational therapists focus on coordination and activities of daily living. They can provide patients with many suggestions for improving daily functions, such as eating, dressing and hygiene. Occupational therapists can also evaluate a home living situation and make suggestions about home safety improvements, especially for patients with disabilities.

For patients with speech or swallowing problems, speech therapists can be extremely helpful. Speech therapists can help patients strengthen their voices, improve volume and articulation, and reduce stuttering. Certain vocal training programs are tailored to the special needs of Parkinson's patients.

All of these types of therapy complement the medical treatment of PD. In addition, they provide a source of expertise and encouragement for a person with PD. Talk to your neurologist about obtaining a referral.

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17. Do acupuncture, hypnosis or massage therapy have a role in treating PD?

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Acupuncture is a form of therapy developed in ancient China involving the insertion of very fine needles into the skin at particular points on the body. Hypnosis is a therapy aimed at inducing a state of relaxation and responsiveness that can be directed towards controlling muscles. Massage therapy is a well-known physical application that is used for muscle relaxation.

None of these techniques has been rigorously tested in PD. It seems unlikely that acupuncture, hypnosis or massage therapies have any effect on the underlying PD, although they can provide relief from aching muscles, which can be of benefit to some patients.



COMMON PROBLEMS IN PARKINSON'S DISEASE

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18. What are dyskinesias?

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Dyskinesias are involuntary twisting or writhing movements that result from excessive dopamine medication. They are drug-induced and are not a sign of PD. These movements typically involve the side of the body most affected by PD, and sometimes can involve the neck, face or trunk. Dyskinesias generally develop after treatment for five years or more using levodopa and dopamine agonists. Long-acting levodopa preparations and COMT inhibitors can worsen dyskinesias. In some individuals, dyskinesias are mild, transient and hardly noticeable. In others, the dyskinesias are severe flailing movements that attract attention and impair coordination and gait.

If dyskinesias become a problem, the solution is to reduce the amount of dopamine medication, whether levodopa or dopamine agonists. Sometimes adding amantadine can reduce the amplitude and severity of dyskinesias. Reducing the dose of COMT inhibitor or switching from a long-acting levodopa preparation may help. Surgery for PD, although a last resort for treating dyskinesias, is very effective.

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19. What are “wearing-off spells”?

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“Wearing-off” is what happens when a patient’s anti-PD medications lose their long-lasting effect. Several hours after a dose of medication, the PD tremor returns, and patients enter a state of increasing parkinsonism. For some, this experience is an inconvenience that can be relieved by taking an extra dose of medication. For others, the wearing-off spells are unpleasant and disabling. Wearing-off spells may occur gradually and predictably, or they may happen suddenly and unexpectedly. Patients who experience wearing-off spells may have their daily routine divided between “off” periods and “on” periods. When they are “off”, their medications are not

working and they are stiff and slow; when they are “on”, their medications have kicked in effectively and they are mobile and independent.

Wearing-off motor fluctuations generally develop within five years of treatment with anti-PD medication. These episodes can be helped by an extra dose of dopamine agonist or levodopa, or by shortening the interval between doses. The addition of long-acting levodopa or a COMT inhibitor can extend the medication effect, and reduce wearing-off. Apomorphine is an injectable dopamine agonist that works within minutes, and can help patients with sudden wearing-off spells. In some people, these strategies may increase the risk of dyskinesias.

Some patients experience wearing-off spells *and* drug-induced dyskinesias. These individuals often require a complicated medication schedule that provides frequent dosing throughout the day. Patients with these problems require close attention from specialists in PD who are knowledgeable about the pharmacology of treating PD. In addition, neurosurgical procedures for PD can be very effective at reducing wearing-off and dyskinesias.

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20. Is depression a common problem in Parkinson’s disease?

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Almost everyone at some time suffers from minor symptoms of depression, often in response to the loss of a loved one, to the loss of a job or to the diagnosis of a chronic illness. Individuals with PD are especially prone to depression because the illness is chronic and can be disabling. PD causes the loss of certain brain chemicals that appear to be related to depression, such as serotonin and norepinephrine, in addition to the depletion of dopamine. For this reason, many research scientists feel that patients with PD are more likely to be depressed than are patients with other chronic illnesses.

Up to 30–50 percent of patients with PD experience mild or moderate symptoms of depression.

Mild depression causes feelings of sorrow, discouragement and passivity, which may be temporary and normal reactions to the disappoint-

ments of everyday life. At the other end of the spectrum, depression can cause an extreme state of hopelessness, low self-esteem or the desire to harm oneself, coupled with severe changes in behavior including insomnia, loss of appetite, loss of interest in daily activities, and social isolation. Some patients with depression also experience feelings of anxiety or panic. In its most severe form, depression can cause a wish to die, which, if untreated, can lead to death by suicide.

If you or your loved one with PD experiences symptoms of depression, it is very important to bring this to your physician’s attention. Often, depression can be lifted by an adjustment in medication and an attempt to re-engage in daily routines. Improvements in mobility, diet and sleep quality can help depression. Many patients benefit from an antidepressant, and there are many effective agents that interact well with PD medication. For more pronounced or sustained symptoms of depression or anxiety, your physician will recommend consultation with a psychiatrist.

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21. Do people with Parkinson’s disease experience hallucinations?

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Usually considered a side-effect of dopamine medication, hallucinations are common in PD. Hallucinations generally occur in the evening or at night, when visibility is reduced. Patients typically experience visual hallucinations. Sometimes they imagine small animals or children; sometimes they perceive faces, or have the impression of figures standing in their presence. Sometimes the hallucinations are threatening, or seem part of a paranoid thought. Most people with Parkinson’s are aware that their hallucinations are a trick of the mind, but others find their hallucinations convincingly real.

If you are experiencing hallucinations, vivid dreams or unusual ideas, bring these to the attention of your neurologist. These phenomena are likely to be induced by your medication, especially dopamine agonists. Often, the hallucinations can be eliminated by adjusting the dose of medication. Sometimes, however, hallucinations are persistent, and require treat-

ment using an antipsychotic agent, such as quetiapine or clozapine.

Q 22. Is dementia part of Parkinson's disease?

A Some people with Parkinson's may develop dementia. In addition to memory problems, PD patients with dementia can have slowed thought processes, difficulties concentrating, apathy and poor motivation, deficient visuospatial processing and poor judgment. Studies suggest that dementia is more common in patients whose PD begins after age 60, or in patients whose PD is characterized primarily by slowness or bradykinesia rather than tremor. Patients with PD and dementia seem to obtain less benefit from their anti-parkinson medications, and are more likely to experience sedation and hallucinations.

There are no effective treatments for dementia but some patients experience an improvement in memory function using the medications for Alzheimer's disease. For others, reducing their dose of PD medications can help to improve mental clarity.

Q 23. Are sleep disturbances part of PD?

A There are many reasons why patients with PD have difficulty sleeping: nocturnal tremors, physical discomfort related to stiffness or rigidity, inability to roll over in bed, bladder problems, restlessness and painful dystonia. Many patients experience vivid dreams or hallucinations and act out violent nightmares. Some individuals fall into a pattern of excessive sleepiness during the day and insomnia at night, causing a "sleep-wake reversal" pattern. It is important not to overlook medical causes of poor sleep, such as sleep apnea.

The treatment for insomnia includes measures to make a patient more comfortable at night. Avoidance of stimulants in the evening, such as caffeine or chocolate, is important. Fluid intake should be limited before bedtime to prevent frequent awakenings to empty the bladder. Some patients are helped by an extra dose of their anti-PD medications. Others require a sleeping medication. Good sleep quality is essential in PD, so insomnia needs to be treat-

ed. If you are having a problem sleeping, make sure you discuss this with your neurologist.

Patients who sleep poorly at night may experience intolerable daytime drowsiness. For these individuals, every effort should be made to improve nocturnal sleep quality and duration. Some of these patients are more alert when their anti-PD medications are reduced, while others benefit from daytime stimulants.

Q 24. Why is constipation a problem for people with Parkinson's? Is it related to the medications to treat the disease or is it a symptom?

A For many patients, anything less frequent than a daily bowel movement is constipation. But gastroenterologists define constipation as less than three bowel movements a week. Constipation is a common problem in PD. The causes of constipation include slow transit time through the bowels due to muscular inertia, medication effects, and diet. Inactivity due to PD can cause or aggravate constipation. In addition, some patients with PD experience difficulty with defecation due to rigidity and slowness of pelvic muscles.

The first step to solving constipation is to improve fiber and fluid intake. For some patients, this means a major dietary overhaul, which requires discipline and support. Efforts to become more active will help constipation. Stool softeners are also useful. Laxatives are available if conservative measures prove inadequate, but it is important to use these agents correctly. More aggressive measures, such as enemas, should not be used without medical supervision. If you are suffering from constipation, it is important to discuss the problem with your physician.

Q 25. Do patients with PD experience bladder problems?

A Urinary urgency and frequency are common bladder problems in people with PD. Patients describe being unable to hold their urine once they receive the signal to empty the bladder. If

they also happen to have difficulty moving quickly to a rest room, the result may be an embarrassing accident.

If you experience bladder control difficulty, the first step is to speak with your neurologist. Some patients will require an urological evaluation to assess the situation. In men, for example, prostate disease is a common cause of bladder malfunction that must be distinguished from PD. The treatment for bladder impairment may include changing the routines of fluid intake, avoidance of diuretics, bladder training, medications and sometimes protective padding. It is important to note that many of the medications for incontinence may cause memory difficulties, a factor that needs to be considered in patients with pre-existing cognitive problems.

Q 26. Do people with Parkinson's have pain?

A Painful sensations are an important but under-recognized cause of distress in patients with PD. The potential causes of pain in PD are numerous, and include cramping muscles, rigidity, arthritis or tendonitis, aching due to poor posture and other mechanical factors, painful contractures because of prolonged immobility and painful sustained twisting or posturing, known as dystonia.

In most cases, it is possible to establish the cause of pain in PD by a careful description of the complaints and a thorough neurological examination. If you are suffering from pain, it is important to note the relationship between the pain and your medications. If the pain involves a limb that seems to be twisting or writhing, a likely cause is dystonia. If the pain involves a rigid or immobile joint, such as the shoulder or the hip, the more likely cause is parkinsonian rigidity or arthritis.

Depending on the cause of pain in PD, the treatment may consist of adjustments in anti-parkinsonian medication, physical therapy, anti-inflammatory agents or other types of pain medication. Individuals who experience persistent pain should bring this problem to the attention of their neurologist.

Q 27. What can I do to relieve the cramping in my legs and toes?

A Many people with Parkinson's experience cramps in their legs and toes. Often these symptoms occur at night and interfere with a patient's ability to sleep. Sometimes, the cramps cause the feet and toes to assume painfully forced or twisted postures, known as dystonia. Dystonia usually occurs in patients when their medications have worn off, which typically happens in the early morning hours. Some patients awaken in the morning with painful dystonia in their toes. In most cases, the next dose of medication will probably relieve the symptoms, and no other treatment is necessary. For more severe symptoms, a neurologist may add an additional drug to help relieve the cramping.

Q 28. Why do I seem to have excessive saliva and what can I do about it?

A Excessive saliva in patients with Parkinson's disease does not result from increased saliva production. Rather, it is caused by a lack of spontaneous swallowing, and by slowness of the tongue, mouth and throat muscles. In addition, a flexed neck posture will cause saliva to accumulate at the front of the mouth, which leads to drooling.

The medications for PD can reduce drooling by increasing the mobility of swallowing muscles. In addition, improved neck posture will help. Some patients suck on sour candies, which helps to trigger the swallowing reflex. If drooling persists despite these conservative measures, medications that cause a dry mouth can help restrict saliva production. It is important to note that these medications may have unwanted side-effects, such as memory impairment or constipation. Severe drooling can also be treated using salivary gland injections and surgery, but these aggressive measures are rarely necessary.

Q

29. What can I do to avoid falling?

A

Falling is perhaps the most dangerous complication of PD and can lead to fractures or head injuries. Falls occur for many reasons, including impaired balance, stooped posture, stiffness and slowness. Many patients have a tendency to sway backwards when they stand or pivot. Others have transient hesitation or freezing when they start to walk, when going through a narrow space, when turning or when approaching a target. At every visit to the neurologist, patients should report problems with balance they may have noticed. And at every visit, neurologists should gauge a patient's falling risk by a careful observation of stance, posture, gait, and stability.

There are many effective ways to reduce or eliminate falling. Sometimes, a change in the medications can prevent freezing spells. Patients benefit from gait training and strategies to avoid falls. The use of devices, such as canes and walkers, is helpful to some. However, nothing can substitute for careful and constant vigilance to prevent a fall.

*“It’s all a
factor of
attitude!*

*You can lay
down and take it
or you can
get connected
to the PD
community.”*

Susan K, Oregon



DAILY LIVING WITH PARKINSON'S DISEASE

Q

30. How important is a special diet? Are there any foods that I should avoid?

A

Many patients with PD lose weight because of poor appetite and inadequate food intake. Individuals with PD should ingest a full diet that contains all the daily nutritional requirements. Extra fresh fruits and vegetables provide fiber that will help prevent constipation. Some patients taking levodopa find that protein interferes with the medication effect. Limiting protein intake or staggering the medication dosing to avoid conflicts with meals can help this problem. To be most effective, medications should be taken before mealtimes, on an empty stomach. For patients with swallowing difficulties, a diet of soft foods is helpful. It is very important to take a lot of fluid during the day, which will maintain hydration and help prevent constipation.

Individuals with PD who progressively lose weight for no clear reason should bring this to the attention of their physician, and undergo a careful and thorough medical evaluation.

Q

31. Is there a role for vitamins or other more “natural” supplements in the treatment of Parkinson’s disease symptoms?

A

Many patients use supplementary vitamins and other compounds in their treatment regimen. Despite the lack of supporting research, these patients hope to slow the disease process using antioxidants such as vitamin E, vitamin C, Coenzyme Q10, glutathione and others. Most experts agree that this approach is acceptable, although the cost of these supplements is a drawback.

Q

32. Should a person with Parkinson’s drive?

A

This is one of the most difficult issues that patients and families face. There are few state

guidelines regarding PD and driving. It is known that patients with PD have slowed reaction times and impaired visuospatial processing. Patients with unpredictable wearing-off spells may find themselves unable to move behind the wheel. Cognitive impairment can affect judgment. A minor fender-bender episode, or a tendency to veer across lanes or around corners, calls into question a patient's ability to judge distances accurately.

The general rule is: when family members feel concerned or unsafe about their loved one's driving, it is time to evaluate the situation. Physicians are not required to report the diagnosis of PD to motor vehicle bureaus but they can insist on a driving test. If everyone agrees that an individual with PD is a potential driving risk, it is time to turn the wheel over to a spouse, family member or friend.

Q 33. Is it okay to have a drink before dinner?

A One cocktail or a glass of beer or wine should be acceptable for people with Parkinson's disease, as long as they do not have other medical conditions or take medications that preclude alcohol use. As everyone knows, moderation is the key.

Q 34. What is the role of exercise in PD?

A PD is a disease of stiffness and slowness, fatigue and weakness. The last thing some patients want to do is exercise and tire themselves out, but exercise is essential to PD. Mobility is improved by remaining active. Regular exercise or physical therapy are crucial for maintaining and improving mobility, flexibility, balance and range of motion, and for warding off many of the disease's secondary symptoms, such as depression and constipation.

Patients who motivate themselves to stretch and bend and move about during the daily routine are the individuals who fight PD with the most success. Research has shown that exercise in PD provides benefits that complement the effects of PD medications. Popular options

include motion exercises, dancing, Tai Chi, walking or swimming. Individuals with gait difficulties or balance impairment can also be helped by strategies to improve their mobility. A physical therapist can help design the best exercise program for your needs. In addition, there are many excellent books and videos on exercises for PD.

To help get the most out of the exercise experience, PDF offers *Motivating Moves for People with Parkinson's*. This seated exercise program, available in video and DVD formats, includes 24 seated-and-stimulating exercises that are designed to remedy the major physical symptoms of PD, including stability, flexibility, posture, vocal range and facial animation. For more information or to order your copy, visit the PDF website, www.pdf.org, or call PDF at (800) 457-6676.

Q 35. Is special equipment recommended?

A For individuals with impairments in mobility and balance, simple walking devices, such as a cane or walker, can help to avoid a fall. These devices provide physical support and serve as a reminder to step deliberately and safely. There are many models of walkers available, differing in the number and size of wheels, the type of brakes, the amount of support, seats and baskets. For individuals with severe balance impairment, sometimes the best option is a wheelchair or scooter.

Other kinds of equipment that may be helpful when hand coordination is not good include special utensils that facilitate eating and hygiene activities. Home furnishings and devices that are helpful in the bathroom, such as shower chairs, are also available. Some people who have difficulty climbing stairs find electric stair climbers to be beneficial.

Before buying an expensive piece of equipment, be sure the device is right for you. It is important to discuss with your neurologist and physical therapist the best choice of device, and receive instruction on how to use it properly.

Q

36. What can family members do to help? Should they assist with everything or encourage their loved one with PD to be as independent as possible?

A

The challenge of PD is to remain as independent as possible. For some people, this means doing everything themselves, even if it takes longer. For others, a variable amount of assistance is needed. Sometimes, a patient's ability to accomplish tasks of daily living fluctuates dramatically during the day, depending on how well the medications work. In the "on" medication state, some patients are fully functional and mobile, but in the "off" state, they require assistance for dressing, feeding, transferring and walking.

It is important for family members to recognize the variable and sometimes unpredictable nature of PD disability. By staying alert and offering help when it is needed, they can find the right balance between protecting the patient and encouraging his or her independence.

Of course, some individuals with PD insist on attempting things they should not, such as climbing ladders despite balance impairment, or carrying heavy bags of groceries. Handling these situations requires judgment and tact, and it is important to reach agreement among the family members about setting reasonable limits.

Some patients who no longer wish to perform tasks of daily living may actually be suffering from depression and apathy. It is important that this problem be recognized as separate from the physical challenges of PD. If depression is present, it should be discussed with the treating neurologist since medication or therapy may be necessary.

*“ So far, I’ve
pretty well sailed
through it but it’s
different for each
and every one
of us.”*

Karen B, Colorado



PARKINSON'S RESEARCH – THE FUTURE

Q 37. Why does it take so long for a drug to become available for the general public's use?

A The route from the chemistry laboratory to your medicine cabinet is long and complicated. In the United States, the Food and Drug Administration (FDA) carefully oversees the development, testing, labeling and marketing of all pharmaceutical products. Before the FDA approves a new medication, it requires proof that the drug is beneficial and safe.

PD drugs are designed and developed in the laboratory. If a compound appears to be promising, it is tested in animals to determine the effective dose and safety. Animal models of PD are critical in the testing of new compounds. Only after a new medication passes all tests of animal safety may a study sponsor apply to begin the first human studies, called clinical trials. "Open label" trials are required to measure how well a new compound is tolerated in normal study subjects, as well as patients with PD. To measure a drug's effectiveness at treating PD, carefully-designed, large-scale clinical trials involving hundreds of patients are required.

An essential aspect of clinical trial design is a blinded randomization process, in which patients are assigned to receive either the active medication or a placebo (a non-active substance designed to look like the medication). But neither the treating investigator nor the patient is allowed to know the drug assignment until the study is over.

Sometimes, the FDA requires more extensive drug testing than the manufacturer anticipated, which can delay the process by years. For patients who are living with PD, the pace of new advances in treatment is never fast enough. But patient safety is a top priority, and the FDA's painstaking efforts to ensure that a new treatment is effective and safe are justified.

Q**38. How do I find out about promising new research in PD?****A**

There are several options for finding out about clinical trials and studies. PDF compiles and distributes a list of clinical trials that includes study details, eligibility criteria and contact information in its quarterly newsletter. There is also a website sponsored by the Kinetics Foundation, www.pdtrials.org, that is entirely devoted to matching eligible patients with appropriate Parkinson's disease clinical trials.

To get a patient's perspective on new research, please visit www.pdpipeline.org, a website operated by volunteers with Parkinson's disease. Then there's the federal government website, www.clinicaltrials.gov, which provides information about federally-sponsored clinical trials, and answers to frequently-asked questions. To search industry trials by location, check www.centerwatch.com. If a contact is listed, call the number and ask to speak with a clinical investigator who can provide more specific information on the study.

Q**39. Should I consider participating in a clinical research study?****A**

Yes! Depending on your symptoms and general health, you should think about getting involved in clinical research. Researchers need volunteers to help solve the mysteries of PD, and to develop new treatments. All drugs currently used for PD are available only because others gave their time to help develop them.

There are many advantages to participating in clinical research. Patients receive more medical attention than is possible during routine care. In clinical trials, patients may have access to promising new treatments that are not currently available to the general population. In most trials, the medical care and study medication is provided to patients without cost. Participating in clinical trials may help bring promising drugs to the market more quickly. Most importantly, participation in clinical research allows patients to make a personal contribution to the fight against PD.

Many clinical studies are designed to test new therapies. Others collect important genetic information, and may only require a small amount of time and personal commitment. Both types of research will help to move our knowledge of Parkinson's forward.

It is important to recognize that patients who participate in research are not guinea pigs. Participants in clinical research are carefully protected from harm by research ethics and careful monitoring by review boards. In fact, patients who participate in clinical research tend to receive closer attention and more frequent evaluations than patients in routine clinical practice.

If you are interested in participating in research, speak to your neurologist. For more information about clinical trials and how to decide if joining one is right for you, call PDF at (800) 457-6676 to receive a brochure devoted to explaining these important issues.

Q**40. Will there be a cure for PD?****A**

Currently there is no cure for Parkinson's disease. When a cell in the brain dies, it is never replaced and does not regenerate. Once the cell can no longer make dopamine, no treatment currently available can bring that cell back to life.

Many scientists believe that the cure for PD will come from a deeper understanding of what causes the disease. If the cause of the neurodegeneration in PD can be identified, scientists hope that a specific treatment can be designed to slow, stop or reverse the process. Strategies of treatment in the future may include the delivery of substances or genetic material directly to the parts of the brain where cells are degenerating. It is hoped that nerve growth factors can someday be used to repair injured dopaminergic neurons. Future treatments may involve replacing dying cells using an alternative source of brain tissue, such as modified cells derived from a stem cell line. However, these techniques are in the earliest stages of development. These and other strategies are being pursued by thousands of scientists world-wide who are dedicated to solving PD.

*“Taking
part in a clinical
trial is a small
way that I can
play a part in
moving our
knowledge of
Parkinson’s
forward.”*

Keith S, Texas

Any more questions?

If you find that some of the answers to the questions in this pamphlet are too brief or general, PDF invites your additional questions. If you have a highly specific question and wish for a personalized answer, you are welcome to contact our “Ask the Expert” helpline by calling our toll-free number at (800) 457-6676. You may also submit a written question to our online service using our website at www.pdf.org. If you wish, you may remain anonymous. You are also welcome to sign up for our mailing list if you would like to receive additional printed materials.

In addition to helping patients, PDF also provides funding, advice and information to clinicians and scientists worldwide who specialize in the diagnosis and treatment of Parkinson’s disease, or who are involved in ongoing laboratory-based Parkinson’s research.

NOTES



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