



Parkinson's Disease Foundation

The Parkinson's Disease Foundation® (PDF®) is a leading national presence in Parkinson's disease research, education and public advocacy. We are working for the nearly one million people in the US living with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services.

Since our founding in 1957, PDF has funded almost \$70 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world.

Main Office

1359 Broadway, Suite 1509
New York, NY 10018
P: (212) 923-4700
F: (212) 923-4778

Columbia University Office

710 West 168th Street
New York, NY 10032

Midwest Office

833 West Washington Blvd.
Chicago, IL 60607
P: (312) 733-1893

Parkinson's Disease



Hope through Research • Education • Advocacy

(800) 457-6676
info@pdf.org
www.pdf.org

Parkinson's Disease Q&A

People with Parkinson's are often searching for answers to their questions on how to live better with the disease. This booklet is a compilation of the most frequently-asked questions that we receive through our Parkinson's Information Service (PINS) from people with Parkinson's disease, their families and caregivers.

Some of the questions posed in this publication have simple answers. Others deal with more complicated issues and the answers are still evolving. If you have a question that you would like to discuss further, please call the Parkinson's Disease Foundation (PDF) toll-free at (800) 457-6676 or email us at info@pdf.org.

This publication was written and edited with the help of movement disorder specialists Blair Ford, M.D., PDF Scientific Editor, of Columbia University Medical Center, and Katie Kompolti, M.D., of Rush University Medical Center.

Table of Contents

Understanding Parkinson's Disease	1 – 9
Signs and symptoms	
Causes	
What happens in Parkinson's disease	
Diagnosis	
Neuroprotection	
Treating Parkinson's Disease	11 – 21
Finding the right doctor	
Treatments and surgery	
Additional therapies	
Common Problems in Parkinson's Disease	23 – 33
Dyskinesias and "wearing-off" spells	
Falling	
Depression, dementia and hallucinations	
Sleep disturbances	
Constipation and bladder problems	
Compulsive behaviors	
Pain	
Sexuality	
Cramping	
Excessive saliva	
Daily Living with Parkinson's Disease	35 – 39
Exercise	
Nutrition and dietary supplements	
Driving	
Alcohol	
Special equipment	
Role of the family	
Parkinson's Research: The Future	41 – 44
Drug discovery and development	
New research	
Participating in clinical trials	
Finding the cure	

UNDERSTANDING PARKINSON'S DISEASE



Understanding Parkinson's Disease

Q What are the signs of Parkinson's disease?

A Parkinson's disease (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 disease:

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, or less commonly in the jaw or face. It appears as a shaking or oscillating movement. Because the Parkinson's tremor usually appears when a person's muscles are relaxed, it is called "resting tremor." This means that the affected body part trembles when it is not performing an action. Typically the fingers or hand will tremble when folded in the lap, or when the arm is held loosely at the side. The tremor usually ceases when a person begins an action. Some people with Parkinson's have noticed that they can stop a hand tremor by keeping their hand busy. The tremor of PD can increase under stress or excitement, sometimes attracting unwanted notice. The tremor often spreads to the other side of the body as the disease progresses, but usually remains most apparent on the initially affected side. Although tremor is the most noticeable outward sign of the disease, not everyone with PD develops tremor.

Bradykinesia

Bradykinesia means "slow movement." In addition to slow movements, a person with bradykinesia will probably also have incomplete movement, difficulty initiating movements and sudden stopping of ongoing movement. People who have bradykinesia may walk with short, shuffling steps (this is called festination). Bradykinesia and rigidity can occur in the facial muscles, resulting in a person's "mask-like" appearance. Due to brady-

kinesia a person with Parkinson's may have difficulty performing repetitive everyday functions, such as buttoning a shirt, cutting food or brushing the teeth. The slowness and incompleteness of movement can also affect speaking and swallowing.

Rigidity

Rigidity, also called increased muscle tone, means stiffness or inflexibility of the muscles. Muscles normally stretch when they move, and then relax when they are at rest. In Parkinson's rigidity, the muscle tone of an affected limb is always stiff and does not relax, sometimes contributing to a decreased range of motion. For example, a person who has rigidity may not be able to swing the arms when walking. Rigidity can cause pain and cramping; as a result, many people with Parkinson's disease experience neck, shoulder and leg tightness.

Postural instability

People with Parkinson's disease often experience instability when standing and impaired balance. A person with postural instability may not be able to recover if jostled, and instead may topple over. Some develop a dangerous tendency to sway backwards (called retropulsion) when rising, standing or turning, which may result in a backwards fall. People with balance problems may also have difficulty when pivoting or making turns or quick movements, resulting in a fall.

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 the person recovers. The normal response is a quick backwards step to prevent a fall. Of course, if a person has postural instability, the neurologist is right there to catch him or her.

In addition to the four cardinal signs of Parkinson's disease, there are other motor impairments, which can be, for many, as troublesome as the primary movement symptoms. People with Parkinson's may go through peri-

ods of "freezing," a transient feeling of being stuck to the floor and unable to take a step. This problem can lead to a forward fall. Other symptoms and signs include a weakening of the voice volume, rapid or stuttering speech, an excess of saliva, shrinkage in the size of handwriting, a flexed or stooped posture, constipation, bladder problems and depression. These problems are discussed in this booklet.

It is important to realize that each person's experience is unique, and not every individual develops all of the signs or symptoms of Parkinson's. Some people with Parkinson's experience tremor as the primary symptom, while others may not experience tremor but have balance problems instead.

Q A

What causes Parkinson's disease?

To date, despite decades of intensive study, the cause of Parkinson's disease remains unknown. Many experts think that the disease is caused by a combination of genetic and environmental factors, which may vary from person to person. In some people, genetic factors may play a role; in others, a head injury, illness, environmental toxin or other event may be factors. Scientists have identified aging as an important factor that contributes to Parkinson's in some patients. For example, 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 people with Parkinson's report having a relative with the disease. In large population studies, researchers have found that people with an affected first-degree relative, such as a parent or sibling, have a two-to-three fold increased risk of developing Parkinson's, as compared to the general population. This means that if your parent has Parkinson's, your chances of developing the disease are slightly higher than the risk in the general population.

The vast majority of Parkinson's cases are not directly inherited, but researchers have discovered several genes that can cause the disease in a small number of families. Some of these genes involve proteins that play a role in dopamine cell functions. Parkinson's genes have been found in some patients who developed the disease at an early age, and many now have been named: parkin, PINK1, LRRK2, among others. Because genetic forms of a disease can be studied in great detail in the laboratory, and because understanding the rare genetic forms of Parkinson's disease may help us to understand more common forms of the disease, genetic aspects of PD are currently 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. Epidemiological research has identified several factors that may be linked to PD, including rural living, well water, manganese, herbicide use and exposure to pesticides. Also, a synthetic narcotic agent called MPTP can cause immediate and permanent parkinsonism if injected. These environmental factors are not sufficient to diagnose the cause of Parkinson's disease in individual people. In fact, there is no conclusive evidence that any environmental factor, alone, can be considered a cause of the disease. However, these environmental factors have been helpful in studying laboratory models of Parkinson's disease. Scientists continue to pursue these clues to understand why Parkinson's disease occurs.

Q What happens to brain cells in Parkinson's disease?

A Parkinson's disease occurs when a group of cells in the area of the brain called the substantia nigra begin to malfunction and die. These cells produce a chemical called dopamine. Dopamine is a neurotransmitter, or chemical messenger, that sends information to

the parts of the brain that control movement and coordination. When a person has Parkinson's disease, the dopamine-producing cells begin to die and the amount of dopamine produced in the brain decreases. Messages from the brain telling the body how and when to move are delivered abnormally, leaving a person incapable of initiating and controlling movements in a normal way. For most people, this process leads to the motor symptoms of Parkinson's: 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.

The trigger that starts the cell death process in Parkinson's disease is unknown, and may differ from person to person. Some people appear to carry a gene defect that allows the development of Parkinson's. Others 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 stop or reverse the disease.

Q How is Parkinson's disease diagnosed?

A Parkinson's disease is diagnosed by a neurologist with experience and training in assessing and treating Parkinson's, called a movement disorder specialist. To diagnose the disease, a movement disorder specialist takes a careful neurological history and performs an examination. There are no diagnostic tests for Parkinson's, so the diagnosis rests on the clinical information provided by the patient and the findings on exam. The role of any additional testing is to rule out other diseases that might mimic Parkinson's disease, such as hydrocephalus.

Very mild cases of Parkinson's disease can be hard to identify, even by an experienced neurologist. There are many neurological condi-

tions that mimic the appearance of Parkinson's. A person with symptoms resembling those of PD should consult a neurologist with special training in movement disorders.

Q How important are tests in diagnosing Parkinson's disease?

A There is no standard diagnostic test for Parkinson's disease. Researchers continue to try to develop an accurate "biological marker" of Parkinson's, such as a blood test or an imaging scan. 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 very expensive.

From a practical perspective, the only useful diagnostic evaluation for Parkinson's disease is testing for conditions that mimic the disease. By doing this, physicians can rule out other diseases, such as hydrocephalus and strokes, and come to the conclusion that a person has Parkinson's disease.

Q If a person has Parkinson's disease symptoms on one side of the body, will the symptoms ever show up on the other side as well?

A By definition, Parkinson's is a progressive disease. Although some people with Parkinson's only have symptoms on one side of the body for many years, eventually the symptoms start on the other side. Symptoms on the other side of the body often do not become as severe as symptoms on the initial side.

Q What is drug-induced Parkinson's disease, and what causes it? Is it permanent or reversible?

A Drug-induced parkinsonism is one of the mimics of Parkinson's disease. 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®). Drugs for nausea such as metoclopramide (Reglan®) and prochlorperazine (Compazine®) can also 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 Parkinson's disease 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 medications when visiting the neurologist.

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

A Many people with Parkinson's state that their symptoms first became apparent after a severe shock, such as a head injury, a medical illness, a surgical operation or severe emotional stress. Because Parkinson's disease is a slow degeneration of brain cells occurring over many years before the first symptoms appear, it seems unlikely that any single severe shock causes the

disease. There is no epidemiological evidence that a mild head injury or concussion can lead to Parkinson's disease; the syndrome of parkinsonism and dementia that occurs in some boxers is the result of hundreds of blows to the head over many years.

For a person who associates the onset of Parkinson's with a fall, head injury or an extreme stress, the most likely explanation is that this individual already had mild, unrecognized Parkinson's symptoms, which became more obvious symptoms after the severe event.

Q Does daily stress worsen Parkinson's symptoms?

A Stress means different things to different people and 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. Stress does not cause Parkinson's, but stress of any kind can briefly worsen its 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.

Paradoxically, some people experience temporary improvements in physical ability in certain stressful situations. Some will rise to the occasion at a major event, such as a wedding. Others may surprise their family by performing well at the doctor's office. Certain stressors may be good, and a person with Parkinson's disease should not shy away from a challenge.

Q What is neuroprotection?

A Neuroprotection is the term used to describe treatment that may slow down, stop or reverse the progression of a disease. Although researchers are attempting to develop neuroprotective agents for Parkinson's, no such therapy is currently proven to be effective.

The antioxidant selegiline is sometimes used as

an initial therapy in early Parkinson's, 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 the progression of Parkinson's disease.

Scientists hope to make progress in identifying neuroprotective agents as they learn more about the causes of dopamine cell death. There are currently several clinical trials investigating the neuroprotective potential of various compounds, including the National Institutes of Health-sponsored NET-PD trial (Neuroprotection Exploratory Trials in Parkinson's Disease). For more information on neuroprotection trials visit www.PDtrials.org, a website that lists Parkinson's clinical trials that are enrolling participants.

TREATING PARKINSON'S DISEASE

Treating Parkinson's Disease

Q How can a person find a doctor who is knowledgeable about Parkinson's disease?

A Finding the right doctor is one of the most important steps a person can take in managing Parkinson's disease. The ideal doctor for a person with Parkinson's is a neurologist with training and experience in diagnosing and treating the disease, called a movement disorder specialist, and who is up-to-date and aware of new therapies.

A person should think carefully about the kind of doctor with whom they will work best. Some may want a specialist on the cutting edge of research and science, even if that means that the physician will be less accessible. Others may want a doctor who is more attentive and readily available. Some people are followed close to home, but make several visits a year to a Parkinson's specialist. It may help to make a list of the qualities that are important before the first appointment with a new doctor.

Finding the right doctor may take time. Start by asking other people with Parkinson's (for example, individuals who attend the same support group) to recommend a doctor with whom they have had a good experience. Another way to find a physician is to call the healthcare provider and ask for a list of specialists in the provider's covered network.

People with Parkinson's are best served by a multi-disciplinary approach that provides not only the expertise of a PD specialist, but also the help of a physical therapist, speech therapist, nutritionist and social worker. Some people also require medical consultants in areas such as psychiatry and neurosurgery. It is important that these healthcare professionals are aware of each other and communicate regularly, and that they all know the full list of treatments and medications that each is prescribing.

The Parkinson's Disease Foundation maintains a list of Parkinson's specialists. To find a specialist in your area, call our toll-free helpline at (800) 457-6676 or email info@pdf.org.

Q How often should people with Parkinson's see a doctor?

A Most people with Parkinson's are advised to see their doctor every three to six months, especially if they are taking antiparkinson medications. If a person is experiencing problems with his or her condition or its treatment, more frequent visits may be warranted. Some people remain in regular contact with their doctors by telephone, fax, letter or, increasingly, by email.

Q What is the best treatment for Parkinson's disease?

A There are now many effective medications for Parkinson's. Because Parkinson's is a very individualized disease, each person who lives with it requires a unique treatment plan. For most, the goal of treatment is to reduce the symptoms and therefore to allow a person to function as normally, and with as few side effects, as possible.

To date, all of the available medications for PD work by suppressing the symptoms and signs of the disorder. Although there is great interest in developing a true neuroprotective agent that can slow or stop the progression of PD, no drug has been proven to accomplish this goal. Symptoms like tremor, slowness, stiffness, reduced facial animation, soft speech, stooped posture, difficulty walking and poor balance can all be helped by the medications for PD. Medications work best when they are taken on a regular schedule, and when combined with exercise, good nutrition and adequate sleep.

For many, the choice of medication is dictated by side effects and tolerability. Most of the

medications for PD work by influencing dopamine, the brain chemical that plays an important role in behavior, coordination and mobility. Dopamine drugs are associated with potential side effects, including nausea, drowsiness, low blood pressure, hallucinations and writhing movements, termed dyskinesias. The ideal medication program is one that provides excellent relief of PD symptoms, minimizes side effects and is simple and easy to administer. Unfortunately, for some individuals, the medication schedule can become quite complicated, with multiple agents taken frequently around the clock.

A full description of each medication and its use is beyond the scope of this booklet. In general, there are six categories of medications for PD: (i) levodopa, (ii) dopamine agonists, (iii) COMT (Catechol-Ortho-Methyl Transferase) inhibitors, (iv) MAO (MonoAmine Oxidase) inhibitors, (v) amantadine and (vi) anticholinergics. Within each class of drug, there are many available options.

The most potent medication for Parkinson's disease is levodopa, and its development in the 1960s represented one of the most important breakthroughs in the history of medicine. Plain levodopa produces nausea and vomiting, and so it is combined with carbidopa to prevent this side effect. The well-known combined carbidopa/levodopa formulation is called Sinemet®. There are now many different preparations and strengths of levodopa/carbidopa, including long-acting forms. In addition, there is a combined formulation that includes the COMT inhibitor entacapone, and is called Stalevo®. It is very important that patients are aware which levodopa preparation they are taking. Be especially careful when renewing prescriptions at the pharmacy: it is possible that a different levodopa preparation may be inadvertently substituted, potentially leading to an overdose or underdose.

Carbidopa/levodopa remains the most effective drug for treating PD. Some patients have been reluctant to take this medication, think-

ing it is a last resort that should be delayed as long as possible. But most neurologists agree that delaying treatment too long is unwise, and may put a patient at risk for falling. So the decision to start carbidopa/levodopa is different for every patient, and requires consideration of potential benefits, risks and the availability of practical alternatives.

Dopamine agonists are drugs that stimulate the parts of the human brain influenced by dopamine. In effect, the brain "thinks" it is receiving dopamine, so these drugs help satisfy the brain's need for dopamine. In general, dopamine agonists are not as potent as carbidopa/levodopa, and therefore less likely to cause dyskinesias. Dopamine agonists can be taken alone or in combination with medications containing levodopa. Agonists available in the United States include bromocriptine (Parlodel®), pergolide (Permax®), pramipexole (Mirapex®) and ropinirole (Requip®). As a class, dopamine agonists may cause nausea, hallucinations, sedation (including sudden sleepiness) and lightheadedness due to low blood pressure, so it is important to start at a low dose, increase gradually and be alert for side effects. Pergolide, a powerful dopamine agonist, has been recently associated with heart valve abnormalities, and patients on this drug are advised to undergo an echocardiogram at regular intervals.

A fifth dopamine agonist, apomorphine (Apokyn®), is a powerful and fast-acting injectable medication that relieves symptoms of PD within minutes, but only provides 30–60 minutes of benefit. With a little training, patients, spouses or family members can be taught to administer the agent, using a pre-filled syringe system. The main advantage of apomorphine is its rapid effect. It is used for people who suddenly find themselves in a wearing-off state. Apomorphine causes severe nausea, and so patients using this agent must take an anti-emetic agent. In addition, apomorphine can provoke dyskinesias and other side effects associated with dopamine drugs.

MAO-B inhibitors such as selegiline or deprenyl (Eldepryl®) and rasagiline (Azilect®) block an enzyme in the brain that breaks down levodopa. They have been shown to delay the need for Sinemet® when prescribed in the earliest stage of Parkinson's, and have also been approved for use in later stages of the disease to boost the effects of Sinemet®.

COMT inhibitors such as entacapone (Comtan®) and tolcapone (Tasmar®) represent the newest class of Parkinson's medications. By themselves, these agents do not relieve symptoms of PD. They must be taken with levodopa, and their advantage is that they prolong levodopa's action. COMT inhibitors block the metabolism of levodopa, allowing a larger amount of levodopa to reach the brain, which raises the dopamine level and prolongs its effect. People who take Tasmar® must have regular testing for liver function.

Amantadine (Symmetrel®) is a mild agent for Parkinson's disease that was initially used early in the disease to help tremor. In recent years, amantadine has been useful in reducing dyskinesias that occur with dopamine medication. Amantadine is a well-tolerated drug, but its potential side effects include dry mouth, constipation, bladder problems, ankle swelling and skin rash.

For people with mild Parkinson's disease that consists only of a tremor at rest, treatment with anticholinergic agents may help. Anticholinergics (trihexyphenidyl, benztropine mesylate, procyclidine, among others) do not act directly on the dopaminergic system. Instead, they decrease the activity of another neurotransmitter that controls movement, called acetylcholine. Potential adverse effects of these drugs include blurred vision, dry mouth and urinary retention. Older individuals are also susceptible to confusion and hallucinations on these drugs and it is therefore wise not to use these agents over the age of 70.

In general, early PD is treated using MAO inhibitors, amantadine, dopamine agonists or,

less commonly than previous, anticholinergics. If possible, a simpler drug plan that works well is the best; for most individuals with mild symptoms, a single drug is all that is needed. For more advanced disease, a levodopa preparation may be used, sometimes alone but frequently in combination with a dopamine agonist, amantadine or the other drugs. For the problem of levodopa wearing off, a long-acting preparation of levodopa may be used. In addition, COMT and MAO inhibitors may be added to levodopa to prolong its action.

There are many treatment options for people with PD. Many take a combination of levodopa, agonists, amantadine and other agents, depending on their symptoms. Unfortunately, because the brain's dopamine stores progressively deplete in PD, a person can expect to have greater dependence on medication over time. It is important to note that the medications for Parkinson's do not stop the disease from progressing, so many individuals require more medication as time passes. But the goal of treatment — to keep a person functioning and enjoying life at their highest level — remains the same.

For more information on Parkinson's disease medications, including potential side effects and interactions, visit www.pdf.org/AboutPD. This part of our website includes an up-to-date table of Parkinson's drugs, hints on how to save money and an overview of surgical procedures.

Q Is it true that levodopa should be avoided as long as possible?

A Forty years after its discovery, levodopa remains the most effective medication for Parkinson's disease, and the “gold standard” by which all treatments for Parkinson's are measured. A long-standing debate in the field is: Does levodopa have a protective effect on the underlying Parkinson's, or does it accelerate the disease, or is it neutral? In practical terms: Should levodopa be given in the early

stages of disease, or should it be withheld as long as possible? After nearly 40 years of experience with the medication, which has been taken by millions of people worldwide, there is no definitive answer to this issue.

Some experts advocate early treatment with levodopa because the drug is the most likely to result in a dramatic improvement in quality of life. As described earlier, levodopa is the most powerful agent for reversing Parkinson's symptoms. Other experts state that the dopamine agonists are nearly as effective as levodopa in improving quality of life, especially in early Parkinson's. Dopamine agonists appear less likely to provoke fluctuations and dyskinesias, two complications of treating Parkinson's. Still others argue that the wearing-off spells and fluctuations seen in levodopa-treated patients would occur anyway, because they reflect the progression of disease. Despite a lively debate in the medical literature, no viewpoint has been proven. The argument that levodopa should be postponed because it only works for a limited period of time is not valid.

A multi-center clinical trial, reported in the *New England Journal of Medicine* in 2004, compared two groups of patients: individuals given levodopa at the beginning of their disease, and individuals who were not given levodopa. The levodopa group had better relief of parkinsonism, as expected, but their results on brain imaging were slightly worse; as a result, no firm conclusions could be drawn regarding the relationship of levodopa to the progression of Parkinson's. The best that can be said is that if levodopa has an effect on the underlying disease, whether accelerating it or slowing it down, the effect is likely to be minor.

A reasonable therapeutic compromise, adopted by many experts, is to treat early-stage Parkinson's disease using milder medications, such as amantadine or dopamine agonists, and adding levodopa when it is required for more symptom control. 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.

Q What are the surgical procedures for Parkinson's disease?

A Surgery for Parkinson's disease has come a long way since it was first developed more than 50 years ago. The newest version of this surgery, deep brain stimulation (DBS), was developed in the 1990s and is now a standard treatment. Although it is certainly the most important therapeutic advance since the development of levodopa, it is not for every person with Parkinson's. It is most effective — sometimes, dramatically so — for individuals who experience disabling tremors, wearing-off spells and medication-induced dyskinesias. DBS was first approved by the US Food and Drug Administration in 1997, and has been used successfully in thousands of people.

During DBS, electrodes are inserted into the targeted brain region using MRI and neurophysiological mapping to ensure accurate placement. DBS targets different parts of the brain, including the subthalamic nucleus, globus pallidus and thalamus, all crucial regions for mobility and tremor control. The choice of target depends upon a person's symptoms. In the recent years, the subthalamic nucleus has become the preferred target in the majority of patients with Parkinson's disease. For those who have symptoms on both sides of the body, the surgery must be performed on both sides of the brain. A device called an implantable pulse generator or IPG (similar to a pacemaker) is inserted under the collarbone to provide a continuous electrical current to a part of the brain involved in motor function. After the surgery is accomplished, people must return to the medical center at regular intervals for programming their implanted devices. Patients are given a controller, similar to a remote controller, which allows them to check the battery and to turn

their device on or off. An IPG battery lasts for about three to five years and is relatively easy to replace under local anesthesia.

Like medication treatment, surgery for Parkinson's is not a cure. But it is very effective in suppressing some symptoms, including tremor, bradykinesia and rigidity. Wearing-off spells and dyskinesias can also be dramatically reduced, and 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. Not every person with Parkinson's is a good candidate for surgery. The ideal candidate is responsive to individual doses of levodopa but has reached a stage associated with wearing-off spells or dyskinesias. The individual should have no cognitive impairment and must be in good general health. An effective support system of family or friends is essential to help the person cope with the emotional demands of the surgery. People 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 neurosurgeons who are specially trained in DBS surgery and a dedicated team of clinical personnel who are available for screening, post-operative care and programming the deep brain stimulator.

It is important that a person with Parkinson's who is thinking of surgery be well informed about the procedures and realistic in his or her expectations. For more information on DBS, visit www.pdf.org to request your print copy of the booklet *Deep Brain Stimulation for Parkinson's Disease*, second edition, written by PDF Scientific Editor Dr. Blair Ford.

Q **What other additional therapies are helpful for people who have Parkinson's disease?**

A There are several excellent forms of therapy that can help people with Parkinson's control their symptoms and make daily life easier. Physical therapy may increase muscle strength and flexibility and decrease the risk of falls. A physical therapist can also develop a daily exercise regimen to keep a person mobile.

For people who have speech or swallowing problems, speech therapists can be extremely helpful. Speech therapy can increase voice volume and assist with word pronunciation. Certain vocal training programs are tailored to the special needs of people with Parkinson's. The Lee Silverman technique is a special speech therapy that can be very beneficial to people with Parkinson's. For further information visit www.lsvt.org.

Occupational therapy teaches people alternative methods of performing daily tasks that may pose a challenge, such as eating and dressing. Occupational therapists can also evaluate a home and give suggestions to make the home safer and easier to get around. These tips are especially useful for people with disabilities, and may provide a stronger sense of control when living with Parkinson's disease.

These therapies complement the medical treatment of Parkinson's disease. A word of advice: the best results depend on the amount of effort the person is willing to give. It takes motivation and persistence to carry out the routines of therapy. A neurologist should be able to provide recommendations for therapy and, if needed, a referral. Unfortunately, insurance may not cover all forms of therapy; sometimes supporting letters of necessity are needed.

Q **Do acupuncture, hypnosis or massage therapies have a role in treating PD?**

A 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 psychological 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 treating Parkinson's disease. It seems unlikely that acupuncture, hypnosis or massage therapies have any effect on the disease itself, although they can temporarily provide relief from aching muscles, which can be of benefit to some people.

COMMON PROBLEMS IN PARKINSON'S DISEASE

Common Problems In Parkinson's Disease

Q
A

What are dyskinesias?

Dyskinesias are involuntary twisting or writhing movements that are caused by dopaminergic medications. They are not a sign of Parkinson's disease. These movements usually appear on the side of the body that is most affected by Parkinson's, and sometimes can involve the neck, face or trunk. Dyskinesias generally develop after treatment with levodopa and dopamine agonists for five years or more. Long-acting levodopa preparations and COMT inhibitors can worsen dyskinesias. In some individuals, dyskinesias are mild and hardly noticeable. In others, they are severe flailing movements that attract attention and impair coordination and gait.

If dyskinesias become a problem, the solution is to talk to the treating physician about making adjustments in medications and dosages. Surgery for PD, although a last resort for treating dyskinesias, is very effective.

Q
A

What are "wearing-off spells"?

"Wearing off" is what happens when individual doses of a person's antiparkinson medications lose their long-lasting effect. Several hours after a dose of medication, tremor returns and the person enters 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. People 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 and they are mobile.

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

Some people with Parkinson's experience both wearing-off spells and drug-induced dyskinesias. These individuals often require a complicated medication schedule that provides frequent dosing throughout the day. People with these problems require close attention from a Parkinson's specialist who is knowledgeable about the many medications available to treat the disease. In addition, neurosurgical procedures for Parkinson's can be very effective at reducing wearing off and dyskinesias.

Q
A

What can I do to avoid falling?

Falling is perhaps the most dangerous complication of Parkinson's disease as it can lead to fractures or head injuries. Falls occur for many reasons, including impaired balance, stooped posture, stiffness and slowness. Many people with Parkinson's have a dangerous tendency to sway backwards when they stand or turn. Others hesitate or freeze when taking a first step through a narrow space, attempting to turn or approaching a target. Crowd situations are especially challenging. At every visit to the neurologist, patients should report any problems with balance that they may have noticed. At each visit, neurologists should also gauge a person'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. People with Parkinson's may benefit from gait training and strategies to avoid falls. The use of devices, such as canes and walkers, is helpful to some. Even when a cane is unnecessary for balance, it will make crowds allow space for a person with PD. For those who tend to sway backwards, it is helpful to stay next to walls or counters for support. Nothing can substitute for careful vigilance to prevent falls.

Q

Is depression a common problem in Parkinson's disease?

A

Almost everyone at some time will experience 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 disease. People who live with Parkinson's disease are especially prone to depression because the disease is chronic and can be disabling. Up to 60 percent of people with Parkinson's experience mild or moderate depressive symptoms. In addition to the depletion of dopamine, Parkinson's also causes the loss of certain brain chemicals that appear to be related to depression, such as serotonin and norepinephrine. For this reason, many researchers think that people with Parkinson's are more likely to be depressed than those with chronic diseases.

Mild depression causes feelings of sorrow, discouragement and passivity, which may be temporary and normal reactions to the disappointments 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 people with depression also experience feelings of anxiety or panic. In its most severe form, depression can cause a wish to die, which, if untreated, may lead to suicide attempts.

When a person with Parkinson's experiences

symptoms of depression, it is important to bring this to medical 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 people benefit from an antidepressant, and there are effective treatments that will not interact negatively with antiparkinson medications. For more pronounced or sustained symptoms of depression, a physician may recommend a consultation with a psychiatrist.

Q Is dementia part of Parkinson's disease?

A About two thirds of people with Parkinson's develop dementia. In addition to memory problems, Parkinson's patients with dementia may experience slowed thought processes, difficulty concentrating, apathy and poor motivation, difficulty estimating distances and poor judgment. Studies suggest that dementia is more common in people who develop Parkinson's after age 60, or in people whose Parkinson's is characterized primarily by slowness or bradykinesia rather than tremor. People with Parkinson's and dementia seem to obtain less benefit from their antiparkinson medications, and are more likely to experience sedation and hallucinations.

For some people, reducing the dose of Parkinson's medications can help to improve mental clarity. In 2006, the first and only medication for treating Parkinson's dementia was approved by the FDA. The drug, rivastigmine tartrate (Exelon®), was already approved in the US for treating dementia associated with Alzheimer's disease.

Q Do people with Parkinson's disease experience hallucinations?

A Hallucinations are common in Parkinson's disease and are usually considered a side effect of dopamine medication. People with Parkinson's

generally experience visual hallucinations in the evening or at night, when visibility is reduced. Sometimes they imagine small animals or children; sometimes they perceive faces, or have the impression of figures standing in their presence. In some cases 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.

People who experience hallucinations, vivid dreams or unusual ideas should inform their neurologist. These phenomena are likely to be induced by medication, especially dopamine agonists, and can often be eliminated by adjusting the dose. Reducing dopamine medication in the evening may eliminate nighttime visions. Sometimes, however, hallucinations are persistent and require treatment using an antipsychotic agent, such as quetiapine (Seroquel®) or clozapine (Clozaril®).

Q Are sleep disturbances part of Parkinson's disease?

A People with Parkinson's often have difficulty sleeping due to nocturnal tremors, physical discomfort related to stiffness or rigidity, inability to roll over in bed, bladder problems, restlessness and painful dystonia. Many people experience vivid dreams or hallucinations and act out violent nightmares, a problem called "REM sleep disorder." Some individuals fall into a pattern of sleeping too much during the day and then having 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 an individual more comfortable at night. People with insomnia should avoid stimulants in the evening, such as caffeine or chocolate. They may also want to limit drinking fluids before bedtime to prevent frequent

awakenings to empty the bladder. Some people are helped by an extra dose of their antiparkinson medications. Others require a sleeping medication. Getting a good night's sleep is essential for people with Parkinson's, so insomnia needs to be discussed with a neurologist.

People who sleep poorly at night may experience intolerable daytime drowsiness. For these individuals, every effort should be made to improve nighttime sleep. Some of these people are more alert when their antiparkinson medications are reduced, while others benefit from daytime stimulants.

Q Why is constipation a problem for people with Parkinson's? Is it a side effect of the medications or is it a symptom of the disease?

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

The first step to solving constipation is to increase fiber and fluid intake. For some people, 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 do not work, but it is important to use these agents correctly under the supervision of a physician. More aggressive measures, such as enemas, should not be used without medical supervision. It is important to discuss this problem with a physician.

Q Do people with Parkinson's experience bladder problems?

A Urinary urgency and frequency are common bladder problems in people with Parkinson's. Some describe being unable to hold their urine once they realize that they have to empty their bladder. If they also happen to have difficulty moving quickly to a rest room, the result may be an embarrassing accident. Nocturnal frequency commonly interrupts sleep.

The first step in addressing difficulty with bladder control is to speak to a neurologist. Some people will require a urological evaluation to assess the situation. In men, for example, prostate disease is a common cause of bladder malfunction that must be distinguished from Parkinson's disease. Treatments may include changing the routines of fluid intake, avoidance of diuretics, bladder training, medications and sometimes protective padding. For nighttime frequency, it is wise to omit fluid in the evening, and to avoid caffeine in any form. 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 Can Parkinson's or its medications cause compulsive behaviors such as gambling and compulsive shopping?

A The reward system of the human brain is governed by dopamine, the same chemical that is deficient in Parkinson's. Dopamine plays a major role in the experience of pleasure, reward-seeking, addiction and impulsivity. Because the medications for Parkinson's disease stimulate the brain's dopamine systems, a small group of susceptible individuals unfortunately have developed addictive and compulsive behaviors.

The most common addictive behaviors triggered by excessive dopamine include compulsive shopping, gambling and sexual urges.

Other compulsive behaviors have also been described, and include excessive eating, excessive Internet use, pornography and alcohol or drug use. If unchecked, these behaviors can be very costly, and lead to severe personal and social distress.

These compulsive behaviors are not typical features of Parkinson's disease, and they usually result from the medication, often a dopamine agonist. If you or a loved one with Parkinson's disease develops an uncharacteristic change in behavior of this type, it is important to alert the treating neurologist, who can often resolve the problem by reducing or changing the medication.

Q Do people with Parkinson's have pain?

A Painful sensations are a serious but under-recognized cause of distress for people with Parkinson's disease. At some point in the illness, nearly everyone experiences pain. The potential causes of pain in people with Parkinson's are numerous (and not always directly related to PD), and include cramping muscles, rigidity, arthritis or tendonitis, aching due to poor posture, painful contractures resulting from prolonged immobility and painful sustained twisting or posturing, known as dystonia.

In most cases, it is possible to establish the cause of painful discomfort in people with Parkinson's disease by a careful description of the complaints and a thorough neurological examination. People who suffer from pain should take note of the relationship between the discomfort and the Parkinson's medications. If the pain occurs mostly when medication has worn off, it is most likely a manifestation of "off" rigidity. 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.

For the most part pain in Parkinson's disease is

treatable. Depending on the cause of pain in Parkinson's, the treatment may consist of adjustments in antiparkinson medication, physical therapy, anti-inflammatory agents or other types of pain medication. All individuals who experience persistent pain should inform their neurologist. For severe dystonia, injections of the muscle relaxant botulinum toxin may be dramatically effective. For pain that occurs in the unmedicated "off" state, the best solution is to increase "on" periods through medication adjustment.

Q Is decreased sexuality common in people with Parkinson's?

A Many people with Parkinson's are concerned that they will lose their ability to experience a fulfilling sexual relationship. There are different dimensions to this concern, which vary between individuals, and range from doubts about their physical ability to have an intimate relationship to whether they are still attractive to their loved one.

The evidence from research studies is that people with Parkinson's can enjoy and experience intimate relationships as well as healthy individuals. However, people with Parkinson's are prone to different types of sexual problems. Men with Parkinson's may experience difficulty achieving erections. Women with Parkinson's complain of vaginal dryness and inability to experience orgasm. Both men and women may suffer from a loss of libido due to Parkinson's. Impaired bladder control due to Parkinson's can have an impact on sexual performance. In addition, depression is common for people with Parkinson's disease, and increases sexual difficulties. Many of these problems can be helped, so it is important to discuss these issues with a neurologist.

In addition to decreased sexual functioning, Parkinson's disease is sometimes associated with hyperactive sexual drives and behaviors. Levodopa and dopamine agonists have been linked to increased libido and sexual perform-

ance; in a minority of individuals, these dopamine drugs have caused inappropriate hypersexuality in patients. This problem has a potentially serious impact on a patient and the spouse, and must be brought to the attention of the treating neurologist.

Q How can cramping in legs and toes be relieved?

A Many people with Parkinson's experience cramps in their legs and toes. Often these symptoms occur at night and interfere with sleep. Sometimes, the cramps cause the feet and toes to assume painfully forced or twisted postures, known as dystonia. Dystonia usually occurs when medications have worn off, which typically happens in the early morning hours. 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 Why do people with Parkinson's have excessive saliva? What can be done to address this problem?

A Excessive saliva in people 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 Parkinson's disease can reduce drooling by increasing the mobility of swallowing muscles. In addition, improved neck posture will help. Some people suck on sour candies to help trigger the swallowing reflex. If drooling persists despite these steps, medications can be prescribed to restrict saliva production and cause dry mouth. It is important to note that these medications may have unwanted side effects, such as memory impair-

ment or constipation. Severe drooling can also be treated using salivary gland injections with botulinum toxin. Surgical procedures have been used for the treatment of drooling in other conditions, but these aggressive measures are rarely necessary in Parkinson's.

DAILY LIVING WITH PARKINSON'S DISEASE

Daily Living with Parkinson's Disease

Q Is exercise beneficial for people with Parkinson's disease?

A Parkinson's is a disease of stiffness, slowness, fatigue and weakness. Some people may feel that they do not want to exercise and tire themselves out, but exercise is essential for a person with Parkinson's disease. Regular exercise or physical therapy is crucial for maintaining and improving mobility, flexibility and balance. It is also helpful in preventing many of the disease's secondary symptoms, such as depression and constipation.

People who stretch, bend and move about during the day achieve the most consistent results. Research has shown that exercise in people with Parkinson's provides benefits that complement the effects of its medications. Popular options include motion exercises, dancing, Tai Chi, walking and swimming. Individuals with gait difficulties or balance impairment can be helped by performing specific exercises. A physical therapist can help design an appropriate exercise program. Strategies to break out of freezing episodes and to prevent backwards falling can be developed. In addition, there are many excellent books and videos on exercises for Parkinson's disease.

In order to have physical therapy covered under Medicare or private insurance, a neurologist must "prescribe" it. Just suggesting an evaluation or sessions with a physical therapist will not ensure the costs will be covered.

To get the most out of exercise, PDF offers *Motivating Moves for People with Parkinson's*. This exercise program, available in VHS and DVD formats, includes 24 seated exercises that are designed to address typical Parkinson's movement challenges, including flexibility, balance, posture, vocal range and facial expressivity. For more information or to order your copy, visit www.pdf.org or call (800) 457-6676.

Q **Do people with Parkinson’s need to have a special diet or avoid any specific foods?**

A A balanced, nutritious diet is important in Parkinson’s. Many people with Parkinson’s disease lose weight because of poor appetite and inadequate food intake. The best plan is to maintain a full diet with all of the daily nutritional requirements. Extra fresh fruits and vegetables provide fiber that will help or prevent constipation. Some people who take levodopa may find that protein interferes with the dose of their medications taken immediately before, during or after the meal. Limiting protein intake or staggering the medication dosing to avoid conflicts with meals can help solve this problem. To be most effective, medications should be taken before mealtimes on an empty stomach. For people who have swallowing difficulties, a diet of soft foods may be recommended. It is very important to drink plenty of fluids during the day to keep hydrated, which helps to prevent constipation.

People with Parkinson’s who progressively lose weight for no clear reason should bring this symptom to the attention of their physician, and undergo a careful and thorough medical evaluation. For more information, download PDF’s fact sheet, “Nutrition and Parkinson’s Disease,” at www.pdf.org or request it by calling (800) 457-6676.

Q **Is there a role for vitamins or other “natural” supplements in treating Parkinson’s disease symptoms?**

A Many people add supplementary vitamins and other compounds to their treatment regimen. They may use them in the hope of slowing the disease process with antioxidants such as vitamin E, vitamin C, coenzyme Q10, glutathione and others. However, there is no research to confirm the idea that these substances stop or slow the progression of Parkinson’s. While most of these supplements are not harmful nor

will they interfere with the absorption of the various antiparkinson medications, the treating doctor should be kept informed of all of the supplements a person is taking.

Q **Should a person with Parkinson’s disease drive?**

A Driving poses one of the most difficult issues that people living with Parkinson’s face. Most states do not have guidelines regarding Parkinson’s and driving. However, people with Parkinson’s must take extra caution as they often have slowed reaction times and impaired visuospatial processing. In addition, people with unpredictable wearing-off spells may find themselves suddenly unable to move behind the wheel. The cognitive impairment of Parkinson’s can affect a person’s judgment, which can have consequences on driving. A minor fender-bender, or a tendency to veer across lanes or around corners, calls into question a person’s ability to judge distances accurately. Finally, some patients may suffer from excessive daytime sleepiness and have problems staying awake when driving. Rarely, patients with excessive daytime sleepiness can have abrupt episodes of sleepiness without warning, the so-called “sleep attacks.”

The general rule is that when family members feel concerned about their loved one’s driving, it is time to evaluate the situation. Doctors are not required to report the diagnosis of Parkinson’s to motor vehicle bureaus but they can insist on a driving test. If everyone agrees that an individual with Parkinson’s is a potential driving risk, it is time to turn the wheel over to a spouse, family member or friend. For more information on Parkinson’s and driving, download PDF’s fact sheet, “Driving and Parkinson’s,” at www.pdf.org or request it by calling (800) 457-6676.

Q Is it okay to drink alcohol?

A Moderate consumption of alcohol (one cocktail or a glass of beer or wine) should be acceptable for people with Parkinson's, as long as they do not have other medical conditions or take medications that prohibit alcohol use.

Q Is special equipment recommended to help people with Parkinson's?

A For those who have problems with mobility and balance, simple walking devices, such as a cane or walker, can help to avoid a fall. These devices provide 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. Some walkers even have a laser beam display to cue stepping for patients who experience freezing. For people who have severe balance impairment, sometimes the best option is a wheelchair or scooter. Training on how to use such equipment properly is also needed and can be provided by a physical or occupational therapist.

Other kinds of equipment that may be helpful when hand coordination becomes difficult include special utensils that facilitate eating and other daily 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. Adaptive computer equipment may also be available.

Before buying an expensive piece of equipment, a person should talk with the neurologist for recommendations and possibly for a referral to an occupational therapist. Occupational therapists can help determine the best choice of device and give instruction on how to use it properly. For more expensive items, a prescription from the neurologist or occupational therapist stating that it is a required

piece of equipment will help to have the costs covered — to the extent they may be covered by Medicare or private insurance.

Q How can family members help? Should they assist with everything or encourage as much independence as possible?

A The challenge for individuals with Parkinson's disease is to remain as independent as possible. For some people, this means doing everything themselves, even if it takes longer. For others, varying amounts of assistance are needed. The need for assistance often fluctuates throughout the day and may depend on how well the medications are working at a specific time. In the "on" medication state, some people are fully functional and mobile, but in the "off" state, they may require assistance for daily activities such as dressing, eating and walking.

It is important for family members to recognize the variable and sometimes unpredictable nature of Parkinson's disease disability. By staying alert and offering help when it is needed, family members can find the right balance between protecting the person with Parkinson's and encouraging independence.

Of course, some people 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 people 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 Parkinson's disease. If depression is present, it should be discussed with the treating neurologist, since medication or therapy may be necessary.

PARKINSON'S RESEARCH: THE FUTURE

Parkinson's Research: The Future

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

A The route from the laboratory to the 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.

Parkinson's medications start with development in a laboratory. If a compound appears to be promising, it is then tested in animals to determine the effectiveness and safety. 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. Carefully-designed, large-scale clinical trials involving hundreds of patients are then conducted to measure the effectiveness of a drug in treating Parkinson's.

An essential aspect of clinical trial design is the process of "blinding" and "blinded" randomization. Participants are randomly assigned to receive either the medication being tested or a placebo (a non-active substance designed to look like the medication). Neither the investigator conducting the trial nor the patient is allowed to know if the medication is real or placebo until the study is over. This way, both the investigator and the patient are blinded.

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

Q How do I find out about promising new research in PD?

A There are several options for finding out about clinical trials and studies. First, visit www.PDtrials.org, the website of the *PDtrials* campaign. *PDtrials* is a coalition of Parkinson's organizations, led by the Parkinson's Disease Foundation, dedicated to increasing education and awareness about clinical trials. This site provides up-to-date information on Parkinson's disease clinical trials currently enrolling participants in the US, as well as the latest news and views on what is happening in the world of Parkinson's trials. *PDtrials* also compiles and distributes a list of clinical trials that includes study details, eligibility criteria and contact information two times a year. Request this and other informational materials on clinical trials at www.PDtrials.org or call (800) 801-9484.

To get the patient perspective on new research, visit www.pdpipeline.org, a website operated by volunteers with Parkinson's disease. Then there is the federal government website, www.clinicaltrials.gov, which provides information about federally-sponsored clinical trials and answers to frequently-asked questions.

Q Should I consider participating in a clinical research study?

A Depending on symptoms and general health, a person should think about getting involved in clinical research. Researchers need volunteers to help solve the unanswered questions about Parkinson's and to develop new treatments. All of the drugs currently used for treating Parkinson's disease are available only because other people volunteered their time to help researchers develop them.

There are several advantages to participating in clinical research. Participants may have access to promising new treatments that are not available to the general population. In most trials, the medical care and study med-

ication is provided to patients for free. People who participate in clinical research tend to receive closer attention and more frequent evaluations than patients in routine clinical practice. Participating in clinical trials allows people with Parkinson's the opportunity to receive excellent medical care while helping to bring drugs to the market more quickly.

It is important to note that the types of clinical studies, and a person's level of involvement, vary widely. Many trials are designed to test new therapies and require participants to make several site visits. Others may collect important genetic information, asking participants for only a small amount of time. Both types of research will help to move our knowledge of Parkinson's forward.

Participants in clinical research are carefully protected from harm by FDA protocol, research ethics and careful monitoring by an Institutional Review Board (IRB) at each study site. An IRB is a committee of physicians, statisticians, researchers, community advocates and others. The IRB ensures that a trial is ethical, and that the rights of participants are protected. All clinical trials in the US must be approved by an IRB before they begin.

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 *PDtrials* at (800) 801-9484 to receive a brochure on the clinical trials process.

Q What are the chances of finding a cure for Parkinson's disease?

A Many scientists believe that the cure for Parkinson's disease will come from a deeper understanding of what causes the disease. What is the reason that dopamine neurons in the basal ganglia begin to degenerate and die? If the cause of the neurodegeneration can be identified, perhaps a specific treatment could be applied to slow, stop or reverse its process.

Strategies of treatment in the future may include the delivery of substances or genetic material directly to degenerating brain cells. Future treatment may involve replacing dying cells using an alternative source of brain tissue, such as stem-cell lines or embryonic tissue. However, these techniques are in the earliest stages of development.

For people living with Parkinson's disease and their families, the progress is always too slow. But there are reasons to be optimistic. It is anticipated that many scientific advances will be translated into benefits for people with Parkinson's, and so the hope for a cure is linked with true promise and great optimism.

Any more questions?

In this booklet, we have attempted to answer the questions that are most frequently asked through our Parkinson's Information Service (PINS) via telephone, email and our website. We understand that people with Parkinson's have many questions about living with the disease. We invite the Parkinson's community to use our services to get answers. To access PINS, call us at (800) 457-6676, email info@pdf.org or submit a question to our "Ask the Expert" web service at www.pdf.org. The PDF website also offers free educational materials, including booklets, fact sheets and videos.

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.



Publication Order Form

PDF offers a variety of free educational materials. Use this order form to request your copies.

	Quantity
<i>PDF Introductory Packet</i> <small>(Limited to one per order)</small>	_____
<i>PDF News & Review</i>	_____
<i>Parkinson's Disease Q&A</i>	_____
<i>Diagnosis Parkinson's Disease (Booklet)</i>	_____
<i>Diagnosis Parkinson's Disease (Booklet & <input type="checkbox"/> Video <input type="checkbox"/> DVD)</i>	_____
<i>Web Resources for Parkinson's</i>	_____
<i>Deep Brain Stimulation for PD</i>	_____
<i>Parkinson's Advocacy</i>	_____
<i>Fulfilling the Hope</i> <small>(Please contact PDF to place bulk orders of more than 50 copies)</small>	_____

Ship to:

Name _____

Address _____

City _____

State _____ Zip _____

Daytime Phone _____

Fax _____

Email Address _____

Add me to your email mailing list.

Please send your order to:

Parkinson's Disease Foundation
833 West Washington Boulevard
Chicago, IL 60607

Phone: (800) 457-6676 Fax: (312) 733-1896

Email: info@pdf.org

PINS: The One-Stop Shop for Information on Parkinson's!



Get your questions answered today!

The Parkinson's Disease Foundation (PDF) is proud to announce the expansion of our Parkinson's Information Service (PINS): the "one-stop shop" for answering your questions about Parkinson's disease!

To access PINS:

- Call our toll-free helpline, (800) 457-6676, from 10 AM – 5 PM EST.
- Use our "Ask the Expert" feature found at www.pdf.org to submit a question or find answers to commonly-asked questions.
- Visit www.pdf.org to download PDF publications and order print copies.

*Production and distribution
of this publication has been
made possible through an
unrestricted educational
grant from Novartis
Pharmaceuticals.*

