



Fact Sheet: **Parkinson's Disease and Caregiving**

What is Parkinson's Disease?

Parkinson's disease (PD) is a progressive, neurological disease that mainly affects movement but can also affect cognition. Parkinson's disease results from the destruction of nerve cells in a part of the brain called the basal ganglia.

Different parts of the brain work together by sending signals to each other to coordinate all of our thoughts, movements, emotions, and senses. When we want to move, a signal is sent from the basal ganglia to the thalamus and then to the cerebral cortex, and to all different parts of the brain. Nerve cells in the brain communicate by using chemicals. A chemical (neurotransmitter) called dopamine is produced in a group of cells called the substantia nigra and is essential for normal movement. When the cells die, they can no longer produce and send dopamine, so the signal to move doesn't get communicated. By the time a person starts to experience motor symptoms of Parkinson's, they've already lost approximately fifty percent of their dopamine producing cells. People may experience non- motor symptoms from loss of other neurotransmitters up to ten years before motor symptoms are noticed.

Caregiving for People Living with Parkinson's

Caring for a loved one with PD can be a challenging job especially as the disease progresses. Former caregivers of a loved one with PD suggest doing the following (see more about these at the end of this fact sheet): Get prepared, take care of yourself, get help (don't try to do it all yourself), work to maintain a good relationship with your loved one, and encourage the person with PD for whom you care to stay active.

Preparing for caregiving starts with education. Reading this fact sheet is a good start. There are many more resources available to you in the Resources section of this fact sheet. Early Parkinson's disease usually requires more emotional support and less hands-on care. It is a good time for family members/caregivers to educate themselves about the disease.

Who Gets Parkinson's Disease?

Parkinson's disease, documented in 1817 by physician James Parkinson, is the second most common neurodegenerative disease after Alzheimer's disease. Estimates regarding the number of people in the United States with Parkinson's range from 500,000 to 1,500,000 with 50,000 to 60,000 new cases reported annually.

There is no objective test for Parkinson's disease, so the misdiagnosis rate can be high especially when a professional who doesn't regularly work with the disease makes the diagnosis.

Since Parkinson's is more common in people 60 years old and older, it is expected that the incidence of Parkinson's will increase with the aging of the baby boomers. Although PD is more common in older persons, some people do begin to show symptoms before they are 40 years old. Researchers have identified families who experience an increased incidence of PD with some showing a genetic relationship from known PD genes. However, genetic causes of Parkinson's are rare, only in approximately 6--8 percent of all cases. Most people diagnosed with PD do not have family members with PD. Recent exposure to certain toxins (many years prior to symptoms) may be needed to develop the disease. One common expression is "genetics load the gun, but environmental [exposure] pulls the trigger." Epidemiological studies are actively exploring the relationship between Parkinson's disease and exposure to agents such as herbicides, pesticides, and other toxins.

Symptoms

All persons with Parkinson's do not develop the same symptoms, and the symptoms change over time as the disease progresses. People will experience both motor and non-motor symptoms. Typically, PD motor symptoms start on one side of the body and over time, may progress to both sides. Often, one side is more affected than the other. The primary symptoms of Parkinson's disease are:

- **Tremor:** Not all persons with PD develop tremor, but this is a common symptom. The tremor is described as a "pill rolling" action of the hand/fingers, usually most pronounced at rest, and may lessen with action or movement. Tremor often starts on one side of the body, usually with the hand, but may also involve the arms, feet, legs, and chin.
- **Rigidity or Stiffness:** In addition to making movement difficult, stiffness can also cause muscle aches. This symptom often is initially attributed to arthritis or pain syndromes, and persons often seek medical attention for "frozen shoulder" symptoms or "tennis elbow" and other orthopedic complaints.
- **Slow Movement (bradykinesia), Loss of Movement (akinesia):** Symptoms present with a decreased arm swing on one side or decreased ability to perform usual motor tasks at usual speeds. They can lose the ability to make normal facial expression appearing "mask-like" to the person they are talking with. Family and friends may comment that the person smiles less or appears disinterested when, in fact, they are unable to make the facial muscles move in a way to help express what they are feeling.
- **Balance and Walking Problems:** Initially, persons have difficulty walking at normal speeds or may find it difficult to fully lift a leg causing the foot to "drag" behind the other foot. Or, they may take unusually small steps to move forward or use

several tiny steps to turn around. Eventually, postural problems result in a stooped torso with a noticeable shuffling gait. The resulting body imbalance can cause the person to stumble or to experience near falls. The person may no longer instinctually reach their arm out to "break" their fall putting them at greater risk for injury. Most people do not develop postural problems until many years after they have been diagnosed. Some individuals also experience episodes of "freezing" where they cannot move for several seconds or minutes. This is most common when they are approaching a doorway or other contained or small space.

Although there are no specific tests for Parkinson's disease, there are several ways of making a diagnosis. Usually, a diagnosis is based on a neurological exam that covers evaluation of the symptoms and their severity. If symptoms are serious enough, a trial test of anti-Parkinson's drugs may be used. Brain scans may be made to rule out other diseases whose symptoms resemble Parkinson's disease. There are always two of the above primary symptoms present when a diagnosis of Parkinson's disease is made.

According to the Hoehn and Yahr scale, a commonly used system for describing how the symptoms of Parkinson's disease progress, Parkinson's disease has the following stages:

- **Prodromal symptoms** (those symptoms that may develop many years before diagnosis): Depression, anxiety, fatigue, disturbance of color vision, constipation, loss of smell acuity

(hyposmia), problems with sleep, slowed thinking

- **Stage I:** Motor symptoms on one side of the body
- **Stage II:** Symptoms spread to both sides of the body

Stage III: Balance starts to become impaired

- **Stage IV:** More difficulty with gait; freezing; or small, fast steps. More problems that affect the center of mid-line of the body such as difficulty swallowing, balance, and increased non-motor problems
- **Stage V:** Unable to locomote independently becoming dependent on a wheelchair or other mobility device

Recent research has identified primary non-motor symptoms of Parkinson's disease, which might be experienced up to ten years before the motor symptoms appear. They are:

- Constipation
- Loss of olfaction (smell), decreased acuity
- Sleep disorders (trouble falling asleep, staying asleep, yelling out, or acting out one's dreams)
- Seborrhea (flakiness of skin around nose, forehead, chin)
- Fatigue
- Depression: Approximately 40% of people with PD develop depression, which can be treated with medication and/or counseling. It is important for people with PD and their caregivers to report signs of

depression to the physician. Persons with PD may not acknowledge their depression and resist taking medication to treat this symptom.

People with Parkinson's can develop some of the following symptoms as the disease progresses:

- **Swallowing difficulties (usually a later symptom):** At least fifty percent of people with Parkinson's develop swallowing problems (dysphagia) that may cause the person to drool, to spill food or liquid from the mouth, or to send food to the back of the throat before it is ready to be swallowed. People with Parkinson's and their caregivers should take care to watch for signs of choking, food stuck in the throat, or increased congestion after eating. Due to difficulty coughing and clearing the lungs, people with Parkinson's also run an increased risk of developing pneumonia. Swallowing problems can be helped with speech therapy.
- **Speech problems:** An estimated 60 to 90 percent of people with Parkinson's will develop some difficulty speaking. A person with PD may speak very softly and may be hard to understand (hypophonia). Speech impairment is referred to as dysarthria and is often characterized as weak, slow, or uncoordinated speaking that can affect volume and/or pitch. The voice may sound hoarse or come out in short bursts. Often, speech problems worsen over time.

Speech problems can be helped with speech therapy.

- **Cognitive Issues (processing and using information):** The majority of people diagnosed with PD will experience some degree of cognitive impairment, which increases in severity over time. An individual may experience forgetfulness, distractibility, weakening executive functioning skills (problem solving, planning, multi-tasking), slower mental processing (recalling names, learning new information), and language and visual-spatial difficulties. All medications should be monitored since high doses of some drugs used for Parkinson's can cause cognitive impairment such as hallucinations or confusion.

Active diagnosis and treatment of the motor functions caused by Parkinson's disease occurs to a greater degree than does the diagnosis and treatment of life-impairing cognitive disease-related conditions. Often the family caregiver may notice cognition changes even before the care recipient may see them in him-herself. If you notice cognitive changes, it is valuable information to discuss with the care recipient and to share with their doctor. (See the Parkinson's Disease Dementia section of this fact sheet for more information.)

Additional PD symptoms may include:

- Restlessness/anxiety
- Eyelid Closure (dystonia of the eyelids can occur when a medication dose wears off)
- Difficulty writing (small handwriting)

- Urinary urgency and frequency (a later symptom; multiple trips to the bathroom, accidents)
- Excessive sweating
- Sexual problems (late symptom)

Treatment/Symptom Management

Drug Therapy & Research

If the disease progresses beyond minor symptoms, drug treatment may be indicated. Drug therapy for Parkinson's typically provides relief for 10-15 years or more. The most commonly prescribed medication is L-dopa (levodopa), and this helps replenish some of the depleted dopamine in the brain. Sinemet, a combination of levodopa and carbidopa, is the drug most doctors use to treat Parkinson's disease. Recent clinical studies have suggested, in the younger person, the class of drugs called a "dopamine agonist" (a compound that activates dopamine receptors in the absence of dopamine) should be used prior to levodopa carbidopa (Sinemet) except in patients with cognitive problems or hallucinations. In those older than 75, dopamine agonists should be used cautiously because of an added risk of hallucinations.

Other drugs are also used, and new drugs are continually being tested. It is common for multiple drugs to be prescribed because many of them work well together to control symptoms and reduce side effects. Contrary to past beliefs, starting Sinemet in newly diagnosed people does not lead to early symptoms of dyskinesia (involuntary movements such as twitching or jerking). Current knowledge is that the

disease progression causes dyskinesias and not a "resistance" to the drug.

Quality of life studies show that early treatment with dopaminergic medications improves daily functioning, prevents falls, and improves a person's sense of well-being.

It is very important for people with PD and their family caregivers to work closely with their doctor(s) and to seek advice from a Movement Disorders Specialist who can best manage the more complicated aspects of the disease. Over time, physicians add combinations of drugs, and more frequent dosing is required as the disease progresses. In the more advanced stages, the Parkinson's drugs provide a shorter time period where each dose is effective in controlling symptoms. This shortened benefit from each dose is called "wearing off," and the motor symptoms (and sometimes the non-motor symptoms such as anxiety) return before the scheduled next dose. People with PD need to pay close attention to the times they take their medications and not the length of time the medication helps their symptoms as well as how long the medication effects last before wearing off. This information helps the physician better determine the amount of medication and the schedule for its use.

Side Effects

As with all medication, side effects can be a problem. For some, starting Sinemet may cause dizziness or nausea, and side effects are most severe when the person first begins taking a drug and gradually disappear or lessen with time. Sometimes adding extra "carbidopa" with each tab of Sinemet helps control the nausea.

For other medications, side effects may appear after several years. For example, long-term levodopa use may result in large uncontrollable movements "dyskinesias" or "off" periods where the person will become frozen (can't move) until the next dose of medication is taken or a sensory trick is used; i.e., counting out loud like a march, "One, two, three." Another side effect in the more advanced stages and from larger doses of dopaminergic medications are visual hallucinations where people at first see things in the corner of their visual field. Sometimes these hallucinations can be frightening.

There is a well described side effect from dopamine agonists that everyone who starts this class of medication should know about. Agonists and higher doses of Sinemet may cause impulse control (behavioral) problems. These behaviors vary but may include: Excessive spending, gambling, sex, pornography, or hoarding behaviors. Often reducing or stopping this class of medications stops the behavior. These behaviors can be so embarrassing for the care recipient and their family that too often the topic is avoided when talking with the doctor. Odd as it may feel, keeping track of unusual impulse behavior to report to the neurologist can provide critical medical management information.

Sometimes, in the most advanced stages, a choice has to be made between motor function and cognitive function. High doses of medications may be required to manage the motor symptoms, but these same doses cause hallucinations or paranoia. At this point, a team meeting with all the medical providers and the family is advised to discuss the need to adjust the medications causing the side effects yet

balance the need to help the patient's motor symptoms. Sometimes adding an anti-psychotic medication (such as quetiapine/Seroquel) is helpful. A multidisciplinary team meeting adds value and can help the family weigh the pros and cons of the PD medications with the caregiver and patient's quality of life.

Surgery and Deep Brain Stimulation

Deep brain stimulation (DBS) is a treatment for Parkinson's disease that uses an implantable pacemaker-like device to deliver electrical pulses to parts of the brain involved in movement. The DBS system consists of leads precisely inserted into a specific brain target, the neurostimulator (pacemaker) implanted in the chest, and extension wires that connect the leads to the neurostimulator. Though implantation of the system (DBS surgery) requires a neurosurgical procedure, the treatment itself consists of long-term electrical stimulation. Advantages of DBS include its ability to reduce the high doses of medications (avoiding the systemic side effects of medication), its adjustability (stimulation settings are programmed non-invasively using a wireless programmer by the clinician or a patient programmer), and its reversibility (can turn it on or off). DBS was approved by the Food and Drug Administration as a treatment for PD in 2002; and, according to Medtronic (the manufacturer of the DBS system), more than 80,000 patients have undergone DBS surgery worldwide.

Typical candidates are those who have motor fluctuations or periods of "off" time with troublesome symptoms alternating with periods of "on" time with good symptom control and also with possible

periods of excessive movement (dyskinesia).

Not all patients with Parkinson's disease are good candidates for treatment with DBS. Approximately 10–20 percent of patients considered for possible treatment with DBS include those:

- With idiopathic (arising from unknown cause) Parkinson's disease and not an atypical variety of parkinsonism
- Who still respond, even if briefly during the day, to levodopa-containing medication
- Who are significantly troubled by motor symptoms of Parkinson's disease (slowness, stiffness, shaking, or other movement problems) despite taking an optimized regimen of medications
- Who do not have significant problems with memory or other cognitive functions
- Who do not have significant or untreated mental health issues like depression or anxiety
- Who have considered the likely benefits and potential risks of DBS and find this assessment acceptable for their situation
- Who have reasonable expectations for what DBS likely will and will not do for them

Individuals whose condition meets these criteria are advised to seek a comprehensive evaluation from an experienced DBS team. This may be accomplished by requesting a referral from the patient's neurologist to a DBS center. The best candidates who have the most robust response to DBS tend to be younger than 70 years of age with

few center of the body symptoms such as swallowing and balance problems.

Non-Medical Interventions for Parkinson's disease

Many caregivers and individuals with Parkinson's disease are interested in complementary therapies to supplement medications and other traditional PD treatments. Increasingly, studies are showing that recreational physical activities such as walking, swimming, dance, yoga, and Tai Chi can play an important role for individuals living with Parkinson's disease. Although there is no evidence that non-medical activities can affect disease progression, physical activity may assist with management of the symptoms of the disease while helping to increase enjoyment of life by staying active, having fun, and learning new skills. Innovative programs are increasingly available. For example, one popular program started in New York and replicated in other states and countries offers dance classes for individuals with PD. A San Francisco Bay Area Parkinson Group partnered with the Mark Morris Dance Group, a highly regarded modern dance company, to develop dance classes for persons with Parkinson's disease (PD), friends, and family. Professional dancers teach the classes in a large dance studio with live piano accompaniment. (See the reference section of this fact sheet for more information on these and other programs.)

Consult your doctor and a Parkinson's care team regarding the type of movement you would like to pursue. They can recommend how hard you should be working (intensity) and the duration of the activity. A recommendation from your doctor to

consult with a Physical, Occupational, or Speech Therapist is often useful. These professionals can assist you in evaluating how to use non-medical interventions in a way that best suits your needs.

Related Diagnosis: Lewy Body Dementia (LBD)

[LBD is an umbrella term for Parkinson's Disease Dementia (PDD) and Dementia with Lewy Bodies (DLB).]

Current research is helping to differentiate dementia related conditions in relationship to Parkinson's disease. Doctor's use a 12-month arbitrary rule to aid in diagnosis. When dementia is present before or within one year of Parkinson's motor symptoms developing, an individual is diagnosed with DLB. Those who have an existing diagnosis of Parkinson's for more than a year and later develop dementia are diagnosed with PDD.

In the simplest terms, Lewy bodies are abnormal clumps of proteins that develop in nerve cells. Cholinesterase inhibitors, medications originally developed for Alzheimer's disease, are the standard treatment today for cognitive DLB and PDD symptoms. Early diagnosis is important as DLB patients may respond differently than Alzheimer's disease patients to certain drug and dementia care treatments.

Studies show that 10 to 70 percent of those living with PD will develop some degree of dementia (loss of brain function). This loss affects memory, thinking, language, judgment, and behavior. A few of the signs of dementia in PD include slowed thinking, a more passive (or apathetic) personality, memory problems, and trouble with

decision-making. One particularly troubling symptom for a caregiver is when a care recipient experiences vivid hallucinations or delusions—the seeing or hearing things that are not really present but seem very real to the individual. Frightening or dangerous hallucinations may call for a medical intervention. Use of certain antipsychotic medication can have highly debilitating side effects due to a hypersensitivity to these drugs by many LBD patients. Highly cautious use and careful monitoring by your doctor is critical should the use of these drugs become necessary. It's also important to note that people living with LBD may or may not experience worsened hallucinations and delusions from medication used for PD such as levodopa. An individual can also experience disease induced episodes of paranoia and have sleep/wake cycle disruption.

This challenging, multi-system disorder involving movement, cognition, behavior, sleep, and autonomic function requires a comprehensive treatment approach to maximize the quality of life for both the care recipient and their caregiver. It is very important to pay attention to symptoms of dementia and to search for an expert clinician who can diagnose the condition accurately.

Depression, which is common in both PD and LBD, can display the same symptoms as Alzheimer's disease. Therefore, it is important to work closely with a physician to rule out other possible causes for the changes in behavior and thinking. (Please see the Resource section of this fact sheet to find organizations and other resources dedicated to helping you learn more about these complex dementia related Parkinson's conditions.)

Support for the Caregiver

Get Prepared

Many resources are available online (See the Resource section of this fact sheet for more information), and public libraries have literature on the disease. Whenever possible, accompany the person with Parkinson's to their medical appointments and ask questions of the doctor, nurse, and social worker.

The areas to assess include your loved one's needs (both your perceptions and theirs); your home environment; and your own health, emotional state, and other commitments. The caregiver has to determine how much they can and can't do themselves and what type of outside support is needed. It is also important to assess current and future financial issues such as health insurance coverage, employment (both caregiver and the person with Parkinson's), managing expenses, and if/when to get Power of Attorney.

Take Care of Yourself

Probably one of the most important and sometimes difficult things caregivers can do is to take care of themselves. This includes maintaining mental and physical health by making and keeping your own medical and dental appointments. As a caregiver, it is important to keep your job whenever possible as it provides not only financial help and possibly insurance coverage but also a sense of self-esteem. Join a support group for caregivers, if possible. Support groups help you meet people who are going through what you are going through. They help you vent frustrations, give and receive mutual support, and exchange resource information and coping strategies.

Whenever possible, get your sleep, take breaks, make and keep social activities, and try to keep your sense of humor.

Get Help

Get help—don't try to do it all alone. By getting help, a caregiver can lessen their sense of isolation, and it gives you more confidence in your own caregiving ability. Having help increases your ability to think creatively and helps you get those needed breaks. Help is available through local and community services. These include neighbors, friends, churches, synagogues, senior centers, adult day health, Meals on Wheels, and door-to-door vans. For a fee, there is in-home care for help with cooking, bathing, dressing, and meal preparation. Additionally, a Social Worker from your health plan or hospital can connect you with other services.

Foster a Good Relationship

Lastly, maintaining your relationship and communication with the person with Parkinson's can be the most challenging and rewarding aspect of caregiving. As Parkinson's disease progresses, the roles change, and the person with Parkinson's may go from being an independent head of the household to a very dependent person requiring a significant level of care. However, research shows that despite high levels of strain, caregivers with good quality relationships have reduced depression and better physical health. Remember, as a caregiver your service to your loved one is beyond measure in terms of love, depth of care, and concern.

Resources

Southern Caregiver Resource Center
891 Kuhn Drive, Ste. 200
Chula Vista, CA 91914

(858) 268-4432 | (800) 827-1008 (in CA)
E-mail: scrc@caregivercenter.org
Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic or disabling conditions in San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

**Family Caregiver Alliance
National Center on Caregiving**
(415) 434-3388 | (800) 445-8106
Email: info@caregiver.org
Website: www.caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

National Parkinson Foundation
www.parkinson.org

**Parkinson's Disease Research,
Education and Clinical Center**
www.parkinsons.va.gov/SanFrancisco

**American Parkinson Disease
Association**
www.apdaparkinson.org

This fact sheet was prepared by Family Caregiver Alliance, and reviewed by S. Heath, RN, MS, and E. Lanier, RN, MS, of the San Francisco Veteran's Administration Parkinson's Disease Research, Education, and Clinical Center and R. Riddle, American Parkinson Disease Association. © 2012 Family Caregiver Alliance. All Rights Reserved.

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