Redwood Caregiver Resource Center
1140 Sonoma Ave., Ste. 1B
Santa Rosa, CA 95405
(707) 542-0282 or (800) 834-1636
Fax (707) 542-0552
Email: rcrc@redwoodcrc.org
Serving: Del Norte, Humboldt, Mendocino, Lake, Sonoma, Napa & Solano Counties

Fact Sheet
Parkinson's Disease

What is Parkinson's Disease?

Parkinson's disease (PD) is a progressive, neurological disease that mainly affects movement. 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, 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. Another chemical in the brain, acetylcholine, is controlled by dopamine. When there is not enough dopamine, there is too much acetylcholine, causing the tremors and muscle stiffness that many people with PD experience.

People with Parkinson's often exhibit a "shuffling" gait, tremor of the arms and legs when they are resting, muscle stiffness, and stooped posture. Some individuals also have cognitive (thinking, judgment, memory) problems.

Who Gets Parkinson'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 new cases reported annually. 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.

Symptoms

All persons with Parkinson's do not develop the same symptoms and the symptoms change over time as the disease progresses. The primary symptoms of Parkinson's disease are:

- ***Rigidity or Stiffness:*** In addition to making movement difficult, stiffness can also cause muscle ache and muscles may tire easily. The number of people with PD who experience rigidity is estimated to be between 89% - 99%.

- ***Tremor:*** Estimates of how many people with PD develop tremors range from 69% - 100%. Of those who do develop tremors, only a few develop tremors that are disabling. The tremor is usually most pronounced at rest. Tremors often start on one side of the body — usually with the hand — but may also involve the arms, feet, legs, and chin.

- ***Slow Movement*** (bradykinesia), ***Loss of Movement*** (akinesia): Slowness occurs in 77% - 98% of those diagnosed with PD. Some individuals also experience episodes of "freezing" where they cannot move for several seconds or minutes. This is often called an "on-off" symptom.

- ***Balance and Walking Problems:*** These may result in a stooped appearance and shuffling gait and can cause falls. Most people do not develop postural problems until many years after they have been diagnosed.

Although there are no specific tests for Parkinson's disease, there are several ways of mak-

ing 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. Symptoms usually affect one side of the body more than the other side. There are always two primary symptoms present when a diagnosis of Parkinson's disease is made.

According to the Hoehn and Yahr scale, Parkinson's disease has the following five stages:

- *Stage I:* Symptoms are only on one side of the body
- *Stage II:* Symptoms are on both sides of the body
- *Stage III:* Balance is impaired
- *Stage IV:* Assistance is required to walk and other symptoms are severe
- *Stage V:* Wheelchair bound

People with Parkinson's may also develop some of the following symptoms:

- **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.

- **Memory problems, mental confusion and/or dementia.** Studies have indicated that more than 50% of people with Parkinson's have mild intellectual changes; about 20% have more substantial cognitive impairment. Memory problems in Parkinson's are typically milder than in Alzheimer's disease. In Parkinson's disease, the person may have difficulty concentrating, learning new information and recalling names.

  All medications should be monitored since high doses of some drugs used for Parkinson's can cause hallucinations or confusion. Dementia occurs in 25% to 40% of people with PD. Individuals with cognitive problems, including dementia, cannot be treated surgically for PD as the surgery can make the cognitive problems worse.

- **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 in a monotone (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.

- **Swallowing problems.** 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.

Additional symptoms may include:

- Restlessness
- Difficulty writing
- Anxiety
- Urinary tract infections
- Excessive sweating
- Sexual problems
- Sleep disorders
- Eyelid Closure
- Skin problems
- Lack of Facial Expression

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) which helps replenish some of the lost 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 that the class of drugs called “dopamine agonist” should be used prior to levodopa (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.

It is very important for people with PD to work closely with their physicians. Many of the drugs used to treat Parkinson’s become less effective over time so physicians will often try different combinations of drugs as the disease progresses. People with Parkinson’s respond differently to drugs so they may need to work with their physician to find the drug or combination of drugs that work for them. It may take several weeks or months before a drug begins to work. Many Parkinson’s drugs can also “wear off” in between doses during the day so people with PD need to pay close attention to the times they take their medications and to plan their activities carefully.

Side effects of medications can also be a problem. For some medications the side effects are most severe when the person first begins taking the drug and gradually disappear or lessen. For other medications, side effects may appear after several years. For example, long-term levodopa use may result in large uncontrollable movements (nodding, twitching or jerking) called "dyskinesias," or “on-off” attacks where the person will become frozen (can’t move) for a few seconds or minutes. Confusion may develop as a side effect after about eight years.

Surgery

Surgery for the treatment of Parkinson’s is used when symptoms become very disabling and are not responding to drug therapy. Additionally, people that undergo surgery must be in good health overall, younger than 70, and mentally competent (no cognitive symptoms or dementia). Different symptoms are improved depending on the area of the brain that is targeted. Surgery on the left side of the brain will improve symptoms on the right side of the body and surgery on the right side will improve symptoms on the left side of the body. There are three types of surgery for PD: *lesioning (ablative), deep brain stimulation (DBS),* and *restorative (transplants).*

In lesioning surgery, a very small part of the brain is destroyed. Deep brain stimulation involves the implantation of a small wire in the brain through which high frequency stimulation can be sent by the person to control his or her symptoms. Surgery can be performed bilaterally (both sides) or unilaterally (one side). In most cases, it is recommended that individuals undergo surgery on only one side to begin with and, if successful, their physician may recommend DBS on the other side if needed.

In restorative surgery, new nerve cells are implanted in the brain to take the place of the nerve cells that have died. In the United States, lesioning surgery and one form of DBS (stimulation of the thalamus) have been approved as treatments. Two other forms of DBS and restorative surgery are still considered experimental.

The surgery for both lesioning and DBS is similar. The person’s head is secured in a frame to keep it from moving and imaging is done so that the surgeon has a clear picture of the brain. A small hole is made in the skull and a very thin wire is inserted into the brain. The surgeon uses several methods to determine when the wire is exactly in place, including having the individual move and observing how the wire affects symptoms. For this reason, the person is awake during the surgery.

In lesioning surgery, once the physician has located the specific area for treatment, an electrical current is sent down the wire and a small

area of nerve cells is destroyed. In DBS, the wire is left in the brain and is attached to a small device implanted under the skin on the individual's chest (similar to a pace-maker). Using a magnet, the person can then turn the stimulator on or off. The amount of stimulation can be programmed by the physician to provide the maximum amount of symptom relief. DBS is usually done as two separate surgeries, one to implant the generator and one to implant the wire.

Restorative surgery is still experimental. Two types of restorative surgery are currently being tested, one using human fetal tissue and the other using fetal tissue from pigs. The goal of the surgery is to implant cells (dopamine-producing nerve cells) that will replace those that have died. Several studies have been done and the operations seem to have been successful for some individuals. These surgical options have the added risk of possible tissue rejection. In the future, surgeons may be able to transplant genetically engineered cells from the person's own body and thus lower the risk of rejection. As in drug therapy for PD, new techniques and ideas for the surgical treatment of PD are continually arising.

Lesioning & DBS Surgery

Surgery:
Thalamotomy: Lesioning surgery in which a small portion of the thalamus is destroyed.
Improves: Tremor
Somewhat Improves: Rigidity (stiffness)
Does not Improve: Bradykinesia

Surgery:
Pallidotomy – Lesioning surgery in which a portion of the globus pallidus is destroyed. Long-term studies indicate that the improvements may last for five years or longer.
Improves: Dyskinesia
Rigidity
Tremor
Somewhat Improves: Balance
Freezing
Walking
Soft speech

Surgery:
STN DBS — Deep brain stimulation of the sub-thalamus nucleus. May be the most promising surgery. Not approved by FDA.
Improves: Slowness
Rigidity
Tremor
Dyskinesia
"On-Off" problems
Increases "On" time
Reduction in levodopa needed

Surgery:
Thalamus DBS — Deep brain stimulation of the thalamus
Improves: Tremor

Surgery:
GPi DBS – Deep brain stimulation of the globus pallidus, pars interns. Usually done bilaterally. Not approved by FDA.
Improves: Dyskinesia
Somewhat Improves: More "On" time
Tremor
Slowness
Rigidity

Parkinson's and Dementia

People with PD who develop dementia tend to be older and to have developed the disease later in life. It is very important to have the dementia diagnosed accurately. Depression, which is common in people with PD, can sometimes cause the same symptoms as dementia. Also some of the medications used for PD can cause hallucinations. These medications can also make the symptoms of dementia worse. In older people, the dementia may not be a symptom of PD but could be a symptom of Alzheimer's disease. Therefore it is important for the person with PD and the family caregiver to work closely with his or her physician to rule out other possible causes for the changes in behavior and thinking.
Some of the signs of dementia in PD include slowed thinking, a more passive personality,

memory problems, and trouble with decision-making. There is a form of dementia called Dementia with Lewy Body (DLB), in which the person suffering from dementia also shows signs of PD such as slowness of movement, stiffness, tremor and falls. In general, if a person who has been diagnosed with PD begins to show signs of dementia within 18 months, it is likely that they have DLB rather than PD. People with DLB do not respond well to the medications used for PD such as levodopa. Dementia in DLB is different from that in PD. In DLB people may have very vivid hallucinations or delusions.

Living Well with Parkinson's

Care for people with Parkinson's includes a well-balanced diet and regular exercise. Physical, occupational or speech therapy may be indicated for some people. Physical therapy and muscle strengthening exercises can be a key part of managing Parkinson's disease. A physical therapist can help develop and monitor a home exercise program. A good exercise routine should include strengthening and flexing all limbs, stretching legs and feet, walking, facial and breathing exercises, and specific exercises to gain better control in swallowing. An occupational therapist can help with walking and accomplishing everyday activities. People with PD lose the ability to move automatically. A good exercise program can help people with PD learn how to think about their movements and to plan their movements one step at a time. "Move it or lose it" is a phrase that most people with PD learn to live by.

A speech therapist can help improve voice volume, quality, and articulation. Therapeutic exercises, including verbalizations and tongue movements, often can make a difference. In some cases where speech is severely impaired, a machine or computer-generated voice can be used. It also may be important for families to learn new strategies to help the person communicate. If the person is confused, for example, it may be necessary to use verbal cues to understand or assist. The inability to articulate can be very frustrating. Offer reassurance and support. This may alleviate some of the person's anxiety over not being able to express a thought or need.

Diet also plays an important role in keeping a person with PD healthy and as active as possible. Choose foods that are easy to eat when someone is having problems swallowing. It is also important that people get enough nourishment. Some physicians recommend that people taking levodopa eat foods that are lower in protein because protein can make the levodopa less effective.

It is also very important for the person with PD and his or her caregivers to take care of themselves emotionally. Support groups can be extremely helpful. Many of the organizations listed in the resource section below offer support groups, counseling and additional information on PD and its treatment.

Credits:

Bronstein, J. M., DeSalles, A., and DeLong, M. R. (1999). Stereotactic Pallidotomy in the Treatment of Parkinson Disease, *Archives of Neurology, 56*, 1064-1069.

Cram, D. L. (1999). *Understanding Parkinson's Disease*, Addicus Books, Inc., Omaha, Nebraska.

Jankovic, J. (1999). New and Emerging Therapies for Parkinson Disease. *Archives of Neurology, 56*, 785-790.

Gleb, D. J., Olive, E. and Gilman, S. (1999). Diagnostic Criteria for Parkinson Disease, *Archives of Neurology, 56*, 33-39.

Sanchez-Ramos, J. R. and Clarence-Smith, K. (Eds.) (2000). Lewy Body Disease and the Similarity to Parkinson's Disease, *Parkinson's Disease Update, Issue 110*, 753-757.

Friedman, J. H. and Fernandez, H. H. (2000). The Nonmotor Problems of Parkinson's Disease, *The Neurologist*, *6*(1), 18 – 27.

National Institute of Neurological Disorders and Stroke (2000). Parkinson's Disease. Hope Through Research.

Resources

Books:

Parkinson's Disease & the Art of Moving, John Argue, (2000), New Harbinger Publications, Inc., 5674 Shattuck Avenue, Oakland, CA 94609,
(800) 748-6273.

Parkinson's Disease: The complete Guide for Patients and Caregivers, A. N. Lieberman (Ed.) and Frank L. Williams, (1993), Fireside/Simon and Schuster, Inc., 1230 Avenue of the Americas, New York, NY 10020 (212) 698-7614.

Caring for the Parkinson's Patient: A Practical Guide (2nd Edition), J. Thomas Hutto, M.D., Ph.D. and Raye Lynne Dippel, Ph.D. (Eds.), (1999), Prometheus Books, 59 Glenn Drive, Amherst, NY 14228-2197, (800) 421-0351.

Parkinson's Disease: A Self-Help Guide, Marjan Jahanshahi, M.D., and C. David Marsden, M.D., (2000), Demos Medical Publishing, 386 Park Avenue South, Suite 201, New York, NY 10016, (212) 683-0072.

Web Sites:

Awakenings: The Internet focus on Parkinson's Disease
www.parkinsonsdisease.com

Parkinson's Disease Webring
www.pdring.com

People Living with Parkinson's
www.plwp.org

People with Parkinsons
www.parkinsoncare.org

We Move
www.wemove.org

Organizations:

American Parkinson Disease Association, Inc.
1250 Hylan Boulevard, Suite 4B
Staten Island, NY 10305-4399
(718) 981-8001
(800) 223-2732
e-mail: info@apdaparkinson.com
web site: www.apdaparkinson.com

National Institute of Neurological Disorders and Stroke
Building 31, Room 8A-06
31 Center Dr., MSC 2540
Bethesda, MD 20892-2540
(800) 352-9424
web site: www.ninds.nih.gov (e-mail is available through the site)

National Parkinson Foundation, Inc.
Bob Hope Parkinson Research Center
1501 NW 9th Ave.
Miami, FL 33136-1494
(305) 547-6666
(800) 327-4545
e-mail: mailbox@npf.med.miami.edu
web site: www.parkinson.org

The Michael J. Fox Foundation
840 Third Street
Santa Rosa, CA 95404
(800) 850-4726
web site: www.michaeljfox.org

Parkinson's Disease Foundation
William Black Medical Research Building
Columbia University Medical Center
650 West 168th St.
New York, NY 10032
(212) 923-4700

Parkinson's Institute
1170 Morse Ave.
Sunnyvale, CA 94089
(408) 734-2800
e-mail: outreach@parkinsonsinstitute.org

Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers. Reviewed by James W. Tetrud, M.D., The Parkinson's Institute and Gary Heit, M.D., Ph.D., Department of Neurosurgery, Stanford University Medical Center. Revised August 2000. *© All rights reserved.*