



Understanding Parkinson's Disease

Important information for you and your loved ones

This handout explains the signs, symptoms, and possible treatments of Parkinson's disease.

Parkinson's disease (PD) is a *hypokinetic movement disorder*. These disorders cause lack of control over body movements.

PD is a *chronic* (long-term) disorder. It slowly progresses over time. It causes nerve cells in the brain (*neurons*) to work incorrectly and then die. Some of these neurons produce *dopamine*, a chemical that sends messages to the part of the brain that controls movement and coordination.

Signs and Symptoms

Major signs and symptoms of Parkinson's include:

- Tremors (shaking)
- Rigid (stiff) muscles
- *Akinesia* (loss of control over movement)
- *Bradykinesia* (slowness of movement)
- Posture problems, such as not being able to sit or stand upright

Other signs and symptoms are:

- Difficulty using small muscles, like those for writing and eating
- Difficulty walking, often with shorter and shuffling steps
- Soft, *monotone* voice (speaking in one tone, with no expression)
- A mask-like face (a person's face may look less expressive than usual because of fewer facial movements)
- General weakness and muscle fatigue
- Cognitive impairment (*dementia*, or not being able to think clearly)
- Other *autonomic* effects (movements or behaviors the person with PD cannot control)

How is Parkinson's disease diagnosed?

Parkinson's may be present years before it is diagnosed. There is no standard test to diagnose or confirm PD. It is diagnosed based on physical symptoms.

The 4 basic symptoms of PD are:

- Tremors and shaking when at rest
- Rigid, stiff muscles
- Bradykinesia
- Not being able to stand or sit upright

Other symptoms include:

- Difficulty with swallowing and chewing
- Problems speaking
- Urinary problems
- Constipation
- Excessive sweating and other problems related to skin
- Emotional changes, such as depression
- Sleeping problems
- *Freezing* (not being able to move)

Living with Parkinson's

What You Can Do

- Work with your doctor to create a plan to stay as healthy as possible. This plan might include:
 - A referral to a *neurologist*, a doctor who specializes in the brain
 - Occupational therapy, physical therapy, or speech therapy to help with moving safely and speaking
 - Meeting with a social worker to talk about how Parkinson's will affect your life and how to plan for changes it will bring
- Start a regular exercise program to slow the progress of the disease.
- If you “freeze” and cannot walk or move forward, ask your family or caregiver for help. They can tell you to rock from side to side while you count silently or out loud. Or, they can tell you to imagine there is a line on the floor, and you need to step over the line. This may help you break the freeze.

- Know that many people with PD have an increased risk of falling. This is because muscle stiffness, being bent over, shuffling when you walk, and freezing can easily cause a loss of balance.
- Keep walking areas in the home clear. Another common reason people with PD fall is that they often lean or rock backward when they stand, and then suddenly fall back. This may mean moving the bed, chairs, bedside table, and other things out of the way so that you do not fall against them.
- Do not go up or down stairs if you are carrying packages in both hands. Leave one hand free to hold a handrail.
- Ask for help with walking if you are:
 - Walking uphill or up a ramp
 - In a crowded area
 - Walking on a broken sidewalk or other uneven surface
 - Trying to avoid things on the floor
 - Walking on icy pavement or a slippery floor
- Work with your doctor to create a medicine schedule that works best for you. Most people with PD take several different medicines to manage their symptoms. Without medicines, your problems with balance, talking, chewing, and swallowing may continue to get worse.
- Find ways to manage your medicines. Here are some tips:
 - Create a calendar or a notebook where you keep track of your medicine schedule.
 - Use a timing device such as a watch with an alarm, a smart phone, or another alarm to remind you when to take your pills.
 - Use a pill organizer labeled by the day and the times to take your medicines.
 - Fill all of your prescriptions at the same pharmacy. This will help avoid possible harmful *drug interactions* (how the drugs you take affect each other in your body).
- Ask your family and friends for support and help.

What are “wearing-off spells”?

“Wearing-off” spells occur when a dose of anti-Parkinson medicine loses its effect. The result is that many hours after taking the medicine, tremor and stiffness return.

Wearing-off spells are unpleasant and disabling. For some people, they can be eased by taking an extra dose of medicine (such as *dopamine agonist* or *levodopa*), or by shortening the time between doses.

If you have wearing-off spells often, you may want to plan a daily routine around the times you are usually “on” and “off.” When you are “on,” your medicines are working well and you are more mobile. When you are “off,” your medicine has stopped providing relief, and you are stiffer and slower.

Ask your neurologist who manages your PD about different medicines to ease the wearing-off spells. There are also surgeries for PD that can help reduce wearing-off spells. These surgeries may also help lessen *dyskinesias* (involuntary movements).

What are dyskinesias?

Dyskinesias are involuntary twisting or writhing movements caused by dopamine medicines: forms of levodopa and dopamine agonists. These movements usually appear on the side of the body that is most affected by Parkinson's. They may also affect the neck, face, or torso.

Dyskinesias can often be helped by having your medicines adjusted. Your doctor may reduce your dopamine drugs or add a drug called *amantadine*. For some people, *deep brain stimulation* (DBS) surgery may be very helpful in reducing dyskinesias. This surgery can be considered if adjusting your medicines does not ease your dyskinesias.

Do people with Parkinson's have pain?

People with PD have many different types of discomfort, including:

- Muscle cramps
- Rigid muscles
- Arthritis (inflamed joints)
- Tendonitis (inflamed tendons)
- Aching because of poor posture
- Painful *contractures* (permanent shortening of muscles), from lack of movement over a long time
- Painful and lasting twisting that causes *dystonia* (holding the head, neck, or torso in an unnatural position)

Pain management may include:

- Adjusting your anti-Parkinson's medicine
- Physical therapy
- Anti-inflammatory drugs or other types of pain medicine

For severe dystonia, your doctor may prescribe injections of the muscle relaxant *botulinum toxin* (BOTOX).

What are the treatment options for PD?

There is no treatment that will slow down or reverse PD. The goal of treatment is to reduce symptoms and to allow you to function as normally and with as few side effects as possible.

Every person who lives with PD needs a treatment plan that is developed just for them. Current treatment options include medicines and surgery such as deep brain stimulation (DBS).

Anti-Parkinson's Medicines

- Medicines prescribed for treatment include levodopa, dopamine agonists, anticholinergic agents, amantadine, and selective monoamine oxidase B (MAO-B) inhibitors.
- Anti-Parkinson's medicines often cause nausea, especially levodopa or dopamine receptor agonists. Make sure you take carbidopa/ levodopa on an empty stomach, at least 30 minutes to 1 hour before breakfast. Avoid high-protein foods such as cheese, eggs, and meat after taking this medicine. If you have nausea, work with your neurologist to adjust these drugs slowly. If you have nausea while taking levodopa, your doctor may add carbidopa to each dose.
- If you are taking rasagiline (Azilect), avoid foods that are high in *tyramine* (an amino acid). These include broad beans, cheese, liver, and wine.

Deep Brain Stimulation Surgery (DBS)

- DBS does not cure Parkinson's.
- *Bilateral* DBS (surgery on both sides of the brain) is often needed to improve walking, although sometimes *unilateral* DBS (surgery on one side of the brain) does help.
- Most of the time, DBS improves tremor, bradykinesia (slowness), stiffness (rigidity), and dyskinesia (involuntary movements). But, it may not get rid of these symptoms completely.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC clinic staff are also available to help.

Neurology Movement Disorders Clinic:
206-598-7688

Neurosurgery Clinic:
206-598-5637

- DBS does not improve symptoms that are still there when you are in your best “on.” For example, if walking and balance do not improve when your medicines are working best, DBS is not likely to improve your walking and balance.
- After DBS surgery, you will have many visits to program the stimulator during the first 6 months. After that, you will have follow-up visits as often as every 6 months. There will be many adjustments to the stimulator and in your medicines.
- DBS lowers the need for medicines for many people, but not for everyone.

To Learn More

For more information on Parkinson's Disease, please visit:

- Parkinson's Disease Foundation: www.pdff.org
- National Parkinson Foundation: www.parkinson.org
- American Parkinson Disease Association: www.apdaparkinson.org

UW Medicine

UNIVERSITY OF WASHINGTON
MEDICAL CENTER

**Neurology Clinic/
Neurosurgery Clinic**

Box 356169

1959 N.E. Pacific St. Seattle, WA 98195
206-598-7688/206-598-5637