



# Parkinson's Disease

UHN

## Information for patients and families

This booklet answers some basic questions about Parkinson's Disease. If you have other questions or need more information, please speak to your health care provider at The Movement Disorder Clinic 416-603-6422



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## Learning about Parkinson's Disease

### What is Parkinson's Disease?

Parkinson's Disease is a disease of the brain that affects movement. It is one of the conditions known as movement disorders.

With Parkinson's Disease, the cells in your brain that make dopamine become damaged and die. Dopamine is a chemical that carries signals between the nerves in your brain. As the cells die, there is less dopamine in your brain.

Without dopamine, these nerves cannot send their signals properly. So, the parts of the brain that control movement cannot properly tell your body how and when to move.

#### Parkinson's Disease is:

chronic	=	lasts forever
neurological	=	affects the nervous system
degenerative	=	slowly gets worse over time

### Who gets Parkinson's Disease?

Parkinson's Disease:

- affects 1 out of 100 adults over age 65
- usually begins around age 60, but can start earlier
- affects more men than women

## What causes Parkinson's Disease?

We do not know the exact cause of all cases of Parkinson's Disease. Research has discovered why the brain cells that make dopamine begin to die in certain people who develop Parkinson's Disease early in life. Research has not yet discovered the cause for forms of Parkinson's Disease associated with ageing.

Parkinson's Disease may be due to:

- an abnormal gene passed down (inherited) from one or both parents
- toxins in the environment such as pesticides
- a person's lifestyle (e.g. lack of regular exercise)
- a combination of the above

## How is Parkinson's Disease diagnosed?

The diagnosis of Parkinson's Disease can be only made by examining the neuron with a microscope (usually after death). Some tests (such as F-dopa PET) can help, but the diagnosis is based on a visit with a doctor called a Neurologist.

The Neurologist makes the diagnosis based on:

- your symptoms
- a physical examination
- tests to rule out other conditions

**Parkinson's Disease can be difficult to diagnose because the symptoms are similar to other conditions.**

## What are the symptoms of Parkinson's Disease?

Not everyone experiences Parkinson's Disease in the same way. The symptoms vary greatly from person to person.

Parkinson's Disease begins very slowly. The early symptoms may be hard to notice. Many patients begin to have symptoms many years before they develop a motor problem. These early symptoms may include:

- difficulty smelling scents
- constipation
- talking during sleep
- moving arms and legs during dreams

The first motor sign is often a slight trembling in one hand. But, many patients do not have any shaking. They can have a stiff or slow moving leg or arm (when they write or walk, for example).

It is common for symptoms to start on one side of the body. Later on they spread to both sides. Symptoms will get worse over time, but how quickly symptoms change is different for each person. It may take years before the disease limits your daily activities or causes disability.

## Common symptoms of Parkinson's Disease

<b>Tremor</b>	<ul style="list-style-type: none"><li>• Shaking or trembling of your hands, arms, legs, jaw or face. This may affect one side of your body more than the other.</li><li>• The tremor is worse when your muscles are resting than during movement.</li></ul>
<b>Rigidity</b>	<ul style="list-style-type: none"><li>• Your muscles and joints are stiff. This can make it difficult to move.</li><li>• Rarely, rigidity can also be painful, especially when you have cramps.</li></ul>
<b>Slower motion</b>	<ul style="list-style-type: none"><li>• Also called bradykinesia</li><li>• Your movements become slower.</li><li>• You may have difficulty starting movements. For example, it can be hard to make your foot move when you want to start walking (like it is “stuck” to the floor).</li><li>• You may have difficulty walking because of shuffling steps.</li></ul>
<b>Poor balance and problems with posture</b>	<ul style="list-style-type: none"><li>• You may lose balance more easily, and tend to fall backward.</li><li>• Your posture becomes stooped.</li></ul>

Over time, you may develop other symptoms such as:

- trouble sleeping
- tiredness
- constipation
- urinary incontinence
- low blood pressure when standing and high blood pressure when lying down
- changes in speech, such as a soft voice, slow or rapid speech
- problems with swallowing
- changes in mood such as depression or anxiety
- changes in memory and thinking

## **Living with Parkinson's Disease**

### **How is Parkinson's Disease treated?**

Treating Parkinson's Disease takes teamwork. You and your family will work with the health care team to find the best treatment plan for you.

The goal of treatment is to relieve your symptoms, increase functioning and quality of life. Research has not yet found a way to prevent or cure the disease, or stop it from getting worse. Although many treatments are now used to effectively treat the symptoms of the disease.

Your treatment plan will depend on your symptoms and needs. Most people take medications to control or relieve symptoms. Some may benefit from surgical treatments. And there is a lot that you can do to help yourself, such as eating well, exercising, learning about your condition and taking part in therapy.

### **Medications**

Taking medications is an important part of your treatment. You may need to take a combination of medications several times a day to control your symptoms. Each medication has a different purpose or way of acting to help relieve symptoms. As your symptoms change over time, the doctor will adjust or change your medications.

After a while, the effect of medications may “wear off” before the next dose. Your health care team can help by prescribing:

- smaller amounts to be taken more often
- long-acting medications
- a combination of medications

Side effects are possible with all medications. Common side effects of medications used to treat Parkinson's Disease are:

- nausea and vomiting
- constipation
- dizziness
- sleepiness
- confusion
- mood changes
- behaviour changes, like wanting to eat more, buy more, gamble or have sex
- hallucinations
- involuntary movements (called “dyskinesias”)

Each person responds differently to medications. Tell your health care team if you have any unwanted effects from your medications. They can give you advice for managing side effects, such as:

- To avoid or reduce nausea, take medications against nausea.
- To prevent constipation, drink lots of water and fluids, and eat foods that are high in fibre (fruits, vegetable and whole grains).
- To prevent dizziness or feeling unsteady from low blood pressure, sit or stand up very slowly. Also your blood pressure should be monitored and your medications might need adjustment.
- To prevent skin damage from the sun (possible when taking medication for Parkinson's Disease), avoid direct sunshine and use protective clothing or sunscreen.
- Do not suddenly stop your medications without consulting your doctor to avoid problems with loss of voluntary movement (also called akinesia), or fever, stiffness, dizziness, fast heart rate, and sweating.

**The goal is to get the greatest amount of symptom relief  
with the fewest side effects.**

## When should I call the doctor?

### Call the doctor right away if you have these signs of an allergic reaction:

- hives, itching or a rash
- swelling of your face, lips, tongue or throat
- difficulty breathing or swallowing

### Other times to call the doctor are when:

- your symptoms are getting worse (medication may need to be changed)
- you wish to stop a medication (some medication must be stopped slowly)
- planning to become pregnant or breastfeed
- had a fall
- have trouble sleeping
- have low mood or a change in mood
- have problems passing urine and bowel movement
- have skin changes or problem, such as lumps and growths on skin
- have fever
- your symptoms are getting worse (medication may need to be changed)

## Common medications

### Levodopa

<b>Other names</b>	Levodopa – with carbidopa (Sinemet <sup>®</sup> , Sinemet CR <sup>®</sup> ) Levodopa – with benserazide (Prolopa <sup>®</sup> ) Levodopa with carbidopa and entacapone (Stalevo <sup>®</sup> )
<b>What does it do?</b>	Levodopa is the most effective medication for controlling symptoms of Parkinson's Disease. Levodopa can have great improvement on shakiness, stiffness, and slow motion.
<b>How does it work?</b>	When levodopa enters the brain it is converted into dopamine. This helps replace the dopamine lost due to Parkinson's Disease. Combining levodopa with carbidopa or benserazide: <ul style="list-style-type: none"><li>• prevents levodopa from being broken down outside the brain, so more of it reaches the brain</li><li>• reduces side effects such as nausea and vomiting</li></ul>

**What side effects are possible?**

- With long-term use or higher doses, you may develop abnormal movements that you cannot control such as twitching or spasms. This is also called dyskinesia. Your doctor may change your medications to reduce this effect.
- nausea
- confusion, hallucination, agitation
- sleepiness
- constipation
- low blood pressure when you stand up suddenly

**Helpful tips**

- Take medication on an empty stomach (30-60 minutes before eating or 2 hours or more after)
- Avoid high protein foods such as meat at lunch (protein reduces absorption of levodopa)
- Do not crush long-acting medications, such as Sinemet CR<sup>®</sup>
- After years of treatment, levodopa may last less. If your symptoms are severe when you wake up, to quicken or increase the effect of levodopa:
  - May crush levodopa and mix it in apple sauce (do not mix in anything that contains protein such as yogurt or milk). Do not crush the long-acting medications.
  - Rinse the medication cup and drink it to ensure the full dose has been taken
  - Follow the levodopa dose with a carbonated beverage to help the medication work more quickly
  - Levodopa can also be chewed, but brush your teeth after to avoid staining
- Sinemet CR<sup>®</sup> tablet and Prolopa<sup>®</sup> capsule should be swallowed whole
- If you have difficulty swallowing, the Prolopa<sup>®</sup> capsule may be opened and contents sprinkled on small amount of food, and taken right away
- Do not stop taking or reduce your medications all of a sudden, without calling the health care team, to avoid problems such as serious fever, severe muscle stiffness, or change in alertness.

## Amantadine

<b>Other names</b>	Symmetrel®
<b>What does it do?</b>	In the early stages of Parkinson's disease, amantidine helps reduce symptoms. When used later on, it helps decrease abnormal movements caused by levodopa (dyskinesias).
<b>How does it work?</b>	It works by increasing the amount of dopamine normally released in the brain.
<b>What side effects are possible?</b>	<ul style="list-style-type: none"><li>• confusion</li><li>• hallucination</li><li>• anxiety</li><li>• drowsiness</li><li>• trouble sleeping</li><li>• nausea</li><li>• difficulty eating</li><li>• blurred vision</li><li>• swollen ankles</li><li>• low blood pressure when you rise quickly from sitting position</li></ul>
<b>Helpful tips</b>	<ul style="list-style-type: none"><li>• Avoid taking amantadine late in the evening to prevent difficulty to sleep.</li><li>• Do not stop taking it all of a sudden, without calling the health care team, to avoid problems such as serious fever, anxiety, hallucinations, and slurred speech. The dose should be tapered slowly.</li></ul>

## Dopamine Agonists

<b>Medications</b>	ropinirole (Requip <sup>®</sup> ) pramipexole (Mirapex <sup>®</sup> ) rotigotine patch (Neupro <sup>®</sup> ) bromocriptine
<b>What does it do?</b>	This medication may be used first, to delay the start of levodopa therapy, or it may be combined with other medications.
<b>How does it work?</b>	Dopamine agonists mimic the action of dopamine in the brain, rather than replace it like levodopa does.
<b>What side effects are possible?</b>	<ul style="list-style-type: none"><li>• low blood pressure when you rise quickly from sitting position</li><li>• sudden sleepiness, falling asleep without warning</li><li>• dizziness</li><li>• confusion, hallucinations</li><li>• nausea</li><li>• constipation</li><li>• swollen ankles</li><li>• sometimes intense urges, such as gambling, compulsive shopping, increased sexual urges, or overeating may occur</li></ul>
<b>Helpful tips</b>	<ul style="list-style-type: none"><li>• Ropinirole, pramipexole and rotigotine patch may be used alone for early Parkinson Disease. As disease worsens they are used in addition to other medications.</li><li>• When applying Neupro<sup>®</sup> patch, avoid using the same area twice within 14 days.</li><li>• To avoid side effects, the dose may be increased slowly.</li><li>• If you do not tolerate one member of this family of medication, you may tolerate another one.</li><li>• Never take two dopamine agonists at the same time</li><li>• Report intense urges for gambling, shopping early, because they can result in financial and social problems.</li><li>• Do not stop taking the medication or reduce the dose all of a sudden, without calling the health care team, to avoid problems such as anxiety, and panic attacks, serious fever, sweating, and muscle rigidity. Gradual dosage reduction is recommended when discontinuing therapy</li></ul>

## MAO-B inhibitors

(monoamine oxidase - B inhibitors)

<b>Medications</b>	selegiline (Eldepryl <sup>®</sup> ) rasagiline (Azilect <sup>®</sup> )
<b>What does it do?</b>	Helps levodopa work longer to control symptoms.
<b>How does it work?</b>	MAO-B inhibitors prevent an enzyme from breaking down dopamine in the brain, therefore increasing dopamine amount in the brain.
<b>What side effects are possible?</b>	<ul style="list-style-type: none"><li>• worsening of abnormal movements</li><li>• headache</li><li>• nausea</li><li>• trouble sleeping</li><li>• dizziness</li><li>• increased heart beat and blood pressure</li></ul>
<b>Helpful tips</b>	<ul style="list-style-type: none"><li>• Medication should not be taken later than noon.</li><li>• You may need to wait two or more weeks between the use of these medications and others, such as antidepressants.</li><li>• Ask your Pharmacist before taking a new prescription or over-the-counter medication, such as a cough and cold medication, muscle relaxant, certain pain medications and herbs.</li><li>• Consult your Doctor for instructions if you are having a surgical procedure done. Rasagiline may need to be held because it can interfere with the anesthetic agent.</li><li>• Do not stop medication suddenly to avoid withdrawal-type reaction, such as confusion, agitation, difficulty with sleep, and convulsions.</li></ul>

## COMT inhibitors

(catechol o-methyltransferase inhibitors)

<b>Medications</b>	entacapone (Comtan <sup>®</sup> ) levodopa with carbidopa and entacapone (Stalevo <sup>®</sup> )
<b>What does it do?</b>	Helps levodopa work longer to control symptoms and decreases “off time”
<b>How does it work?</b>	COMT inhibitors prevent levodopa from being broken down outside the brain, so more of it reaches the brain.
<b>What side effects are possible?</b>	<ul style="list-style-type: none"><li>• worsening of abnormal movements</li><li>• sweat and saliva may become darker</li><li>• urine may become a brownish-orange (it is harmless)</li><li>• nausea</li><li>• diarrhea</li><li>• abdominal pain</li><li>• dizziness</li><li>• low blood pressure when you stand up suddenly</li></ul>
<b>Helpful tips</b>	<ul style="list-style-type: none"><li>• Entacapone is not used alone, but always together with levodopa</li><li>• Do not stop taking your medications all of a sudden without calling the health care team, to avoid worsening of Parkinson’s disease, or symptoms such as fever, severe muscle rigidity, or changes in alertness.</li></ul>

## Anti-cholinergic medications

<b>Medications</b>	benztropine (Cogentin®) procyclidine (Kemadrin®) trihexyphenidyl (Artane®)
<b>What does it do?</b>	Has a mild effect on symptoms of Parkinson's Disease, mainly tremor.
<b>How does it work?</b>	Reduces certain chemicals in the brain to balance with the amount of dopamine.
<b>What side effects are possible?</b>	<ul style="list-style-type: none"><li>• drowsiness</li><li>• confusion</li><li>• constipation</li><li>• memory problems</li><li>• nausea</li><li>• blurred vision</li><li>• dry mouth</li><li>• difficulty emptying bladder</li></ul>
<b>Helpful tips</b>	<ul style="list-style-type: none"><li>• The side effects may make these medications unsuitable for older people.</li><li>• Sucking on sugarless candy, or using moisturizing spray can help with side effects of dry mouth.</li><li>• Do not stop taking your medications all of a sudden without calling the healthcare team, to avoid worsening of Parkinson's symptoms, or unwanted effects such as fever, severe rigidity, changes in alertness, tension, irritability, sweating, fast heart rate, headache, difficulty sleeping, stomach pain, nausea, decreased appetite, or sensitivity to light.</li></ul>

## **Surgery**

Some people have severe symptoms of Parkinson's Disease or do not respond well to medications. They may benefit from surgical treatment, such as Deep Brain Stimulation. This treatment uses electrical impulses to stimulate the area of the brain that controls movement. This can help improve motor function, decrease motor fluctuations, and reduce involuntary movement (dyskinesia). If surgery is an option for you, your doctor will discuss the risks and benefits.

## **Other therapy**

There are many types of therapy that can help you live better with Parkinson's Disease. You may be eligible to receive some of these professional services in your home or community through your local Community Care Access Centre (CCAC).

Physiotherapy can:

- help you stay active
- improve your balance and coordination
- strengthen your muscles
- help improve your sleep and mood

Occupational Therapy can:

- help you with daily activities such as dressing, bathing, writing, driving and working
- help you be as independent as possible
- suggest ways to make living at home safer for you

Speech Therapy can:

- help your voice become stronger and clearer
- help with swallowing and eating

A Dietitian can help you learn:

- about healthy eating
- how to prevent constipation with fluids and high-fibre foods, such as fruits, vegetables and whole grains
- which foods won't interact with your medications

## Education and support

Each member of our health care team will give you information and support. We want to help you and your family make informed decisions and take part in your care.

Your health care team understands what you are going through. You may feel frustrated when simple activities like walking, talking and eating become more difficult. Knowing that your condition will likely get worse can make you feel helpless, anxious, angry or sad. All these feelings are normal. There are resources available to help you learn how to cope and live with this disease.

You may find it helpful to get support from others who have faced the same challenges. We can help you and your caregivers find support groups online or in your community.

## Where can I get more information?

### University Health Network

#### Neuroscience Clinic

- Each member of the health care team can give you information. We welcome your questions at any time.
- Website: [http://www.uhn.ca/KNC/PatientsFamilies/Clinics\\_Tests/Movement\\_Disorders](http://www.uhn.ca/KNC/PatientsFamilies/Clinics_Tests/Movement_Disorders)

#### Movement Disorders Resources

- Website: [http://www.uhn.ca/PatientsFamilies/Health\\_Information/Health\\_Topics/Pages/movement\\_disorders.aspx](http://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Pages/movement_disorders.aspx)

### Parkinson's Society Canada

- Website: [www.parkinson.ca](http://www.parkinson.ca)
- 4211 Yonge Street Suite 316  
Toronto ON M2P 2A9  
Phone: 416-227-9700

### National Parkinson's Foundation

- Website: [www.parkinson.org](http://www.parkinson.org)

### Michael J. Fox Foundation for Parkinson's Research

- Website: [www.michaeljfox.org](http://www.michaeljfox.org)

University Health Network tries to keep patient education resources up to date, but some information may change. Please contact any organizations that may be listed to make sure the information is correct or to find out more about their services. Websites and web links also may change.

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This guide has been reviewed by the Patient and Family Education Program