

Parkinson's Disease

An Introductory Guide

This guide will help you better understand Parkinson's disease. It describes the illness, changes in your body over time, treatment and care options, possible health problems, as well as when and where you can find more help.

**Please review this guide with your family.
Bring it with you to your appointments
with your health care team.**



This material is also available at:
MUHC Patient Education Portal
muhcpatienteducation.ca

This booklet was developed by:

Ron Postuma, MD, MSc
Julius Anang, MD

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To obtain print copies of this book, please contact Parkinson Canada at 1 (800) 565-3000 or email education@parkinson.ca.

IMPORTANT: PLEASE READ

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute for medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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Part 1 Parkinson's Disease: the basics

About this guide

What is Parkinson's disease?

- What movement changes might I see?
- What is happening in my brain and body?
- Who can get Parkinson's?

How we diagnose Parkinson's disease

Treatments for Parkinson's disease - the basics

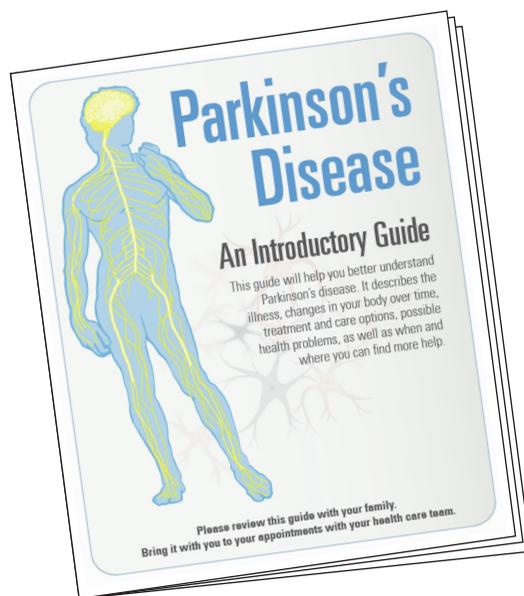
- What you should know about treatment
- What are the treatments?
- Take an active part in your care

About this guide

This guide is a practical introduction to Parkinson's disease. It is meant to help you learn about:

- Symptoms of Parkinson's and how you can spot them
- Treatment and care options
- Tips and strategies for you to take charge of your health
- Possible problems to watch out for
- When and where you can find more help

This book is by no means complete. We aimed to provide a general introduction, to help you understand the basics of your condition. Information about future research, in-depth discussion of the cause of PD, etc. is not the focus. Use this as an introductory guide, to help you take charge and guide you as you plan for what is ahead.



We know that this can be a stressful time for you and your family. The good news is that you are not alone. Your health care team is here to help and will be with you each step of the way.

Using our experience as doctors caring for people with Parkinson's, and what patients and families have told us, we have designed this guide to help you understand your condition. You may wish to review it with your family or friends.

This guide is divided into 3 main parts:

- **Part 1 covers the basics** - what is Parkinson's disease, what causes it, how we confirm whether you have it (diagnosis), and treatment options. Use this as a basic and general introduction, and go to Parts 2 and 3 when you'd like more detail.
- **Part 2 covers changes in body** movement that you might notice over time. We call these changes motor symptoms. Examples include tremors, stiffness, slowness and trouble walking. We describe each of these changes and then focus how they are treated.
- **Part 3 covers all other changes** in your body that you might notice. These are called non-motor symptoms. Examples include changes in your sleep, mood, memory, bowels, bladder, etc. These types of changes may not always be as easily noticed as motor changes. However, spotting them is just as important, as they are also treatable.

Please keep in mind that some information in this booklet may not apply to you. Some problems may not happen for at least another 10 years from now. Others problems described here may never happen to you.

There is a lot to know about Parkinson's, probably more than you can take in all at once. For this reason, we suggest that you focus first on the information in Part 1. Move on to Part 2 and 3 only when you feel ready to learn more. Most importantly, speak to your 'health care team if you have questions or concerns. They can explain how the information in this book may apply to you

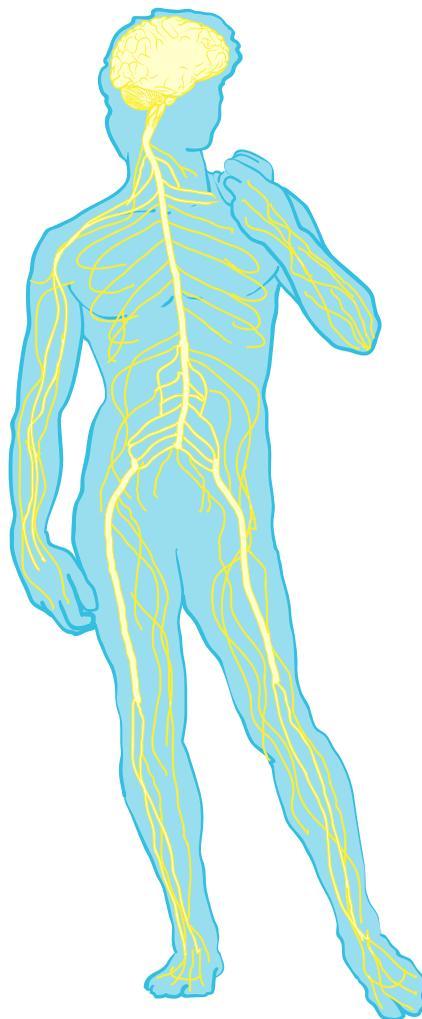
What is Parkinson's disease?

Your nervous system is what allows you to understand, respond to, and make sense of the world around you. It operates all of the other important systems in our body that help you breathe, digest, move, talk, learn, see, hear and so much more.

Parkinson's disease is one of the common illnesses of the nervous system. It is mainly identified by a loss of the ability to move normally. These changes appear slowly. They gradually become worse over time. Symptoms vary quite a bit from person to person. Often, changes start on one side of the body and eventually spread to the other side.

Did you know?

About 100,000 Canadians and 10 million people worldwide live with Parkinson's. The name comes from Dr. James Parkinson, who first described the illness in 1817.



What movement changes might I see?

There are 4 main types of changes in body movement that we see in Parkinson's disease:

1. Slow movement (We call this "bradykinesia".)

Your hand, leg, and face movements become slower and smaller than before. You or your family members may also notice that your voice is softer or quieter. Your face may become less expressive (or "masked"). Your handwriting may become slow and small. You may have fewer spontaneous movements. (These are the many, natural movements that you make throughout the day, without much thought.) Routine activities, such as dressing and showering may take longer than they used to.

2. Shaking (tremor)

You may notice that your hands, legs or jaw are shaky. This typically happens when arms or legs are resting. (For example, your hands might shake when rested in your lap or while walking). Shaking often gets more noticeable during stressful situations or if you are tired. Not everyone with Parkinson's disease experiences shaking.



3. Stiffness (rigidity)

You might not be aware of this sign, but your doctor will pick this up during your check-up. Sometimes stiffness can cause muscle aches.



4. Walking and balance problems

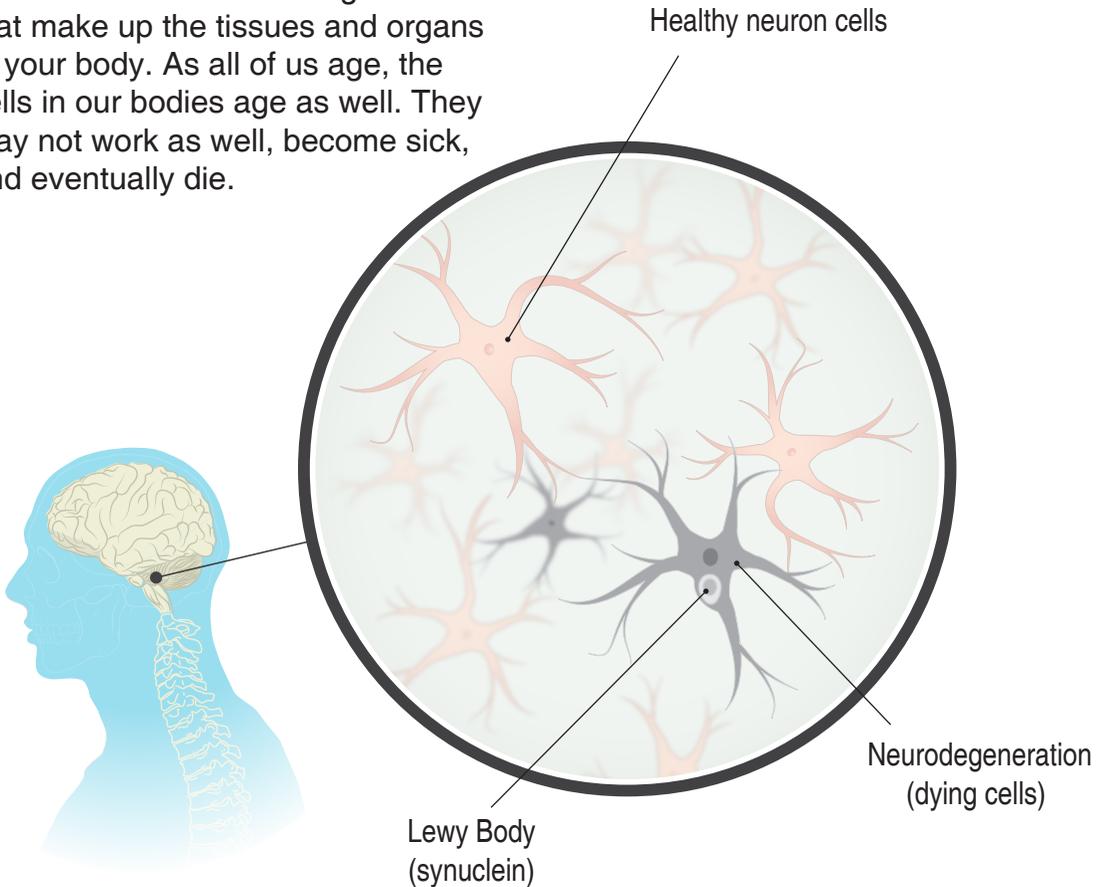
Your walking may slow down. You may begin to take smaller steps or shuffle. You might feel unsteady. After some years with Parkinson's disease, some patients have episodes where their legs briefly get stuck in place, or they can lose their balance and fall.

Along with movement changes, **you may also notice other (non-motor) changes.** These could include difficulty sleeping, loss of smell, problems urinating, constipation, mood changes, trouble swallowing, pain, feeling tired, or troubles with memory. Many of these changes may have started before you noticed the change in your movements. **(For more information, see Section 3 of this guide.)**

Parkinson disease is a chronic illness. This means that it continues over a long period of time, and develops slowly. The good news is that we know quite a lot about Parkinson's. While there is no cure yet, many of the changes and health problems that come with the illness are now treatable. Treatment can ease and help control many of these health problems.

What is happening in my brain and body?

Your body is made up of cells. These cells are the building blocks that make up the tissues and organs of your body. As all of us age, the cells in our bodies age as well. They may not work as well, become sick, and eventually die.

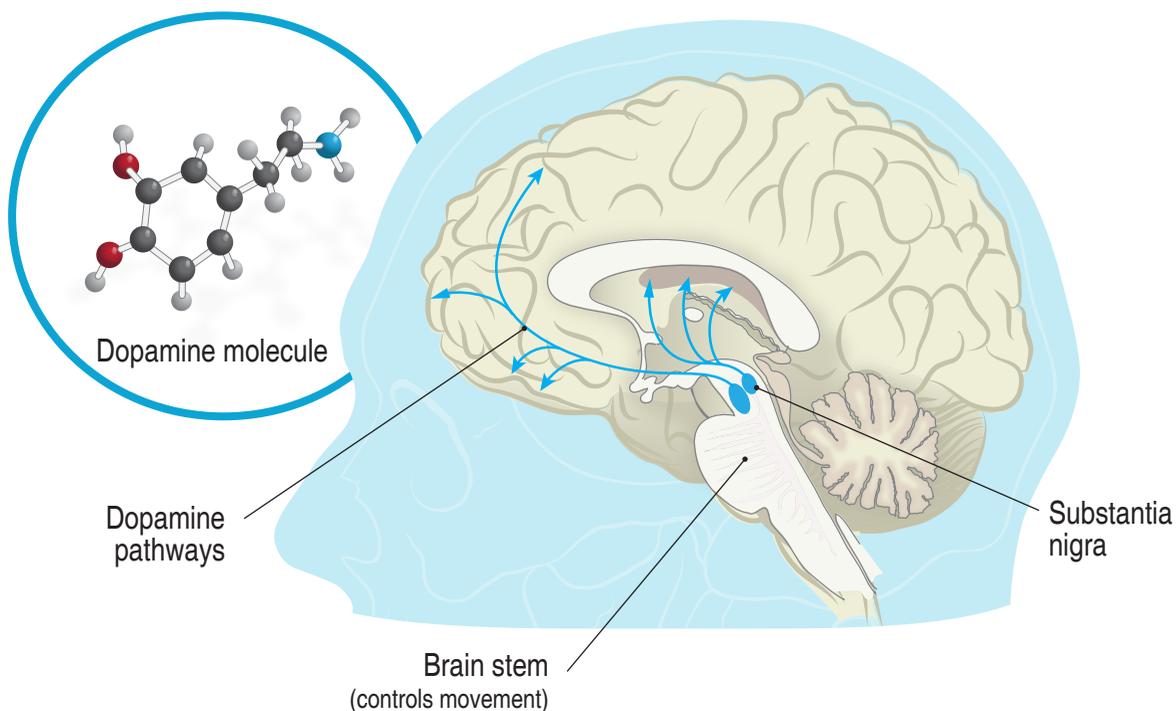


In Parkinson's disease, some areas of your brain are aging faster than the rest of you. So, certain nerve cells (also called neurons) stop working properly over time. Eventually, they die. We call this neurodegeneration.

For most people, Parkinson's aging starts in areas at the base of the brain (the brainstem), as well as in some nerve cells found outside the brain. Over time, it spreads to other parts of the brain.

One part of the **brainstem** (called the **substantia nigra**) is very important area for controlling movement. The cells in this area release a chemical called **dopamine**. Dopamine sends messages to other areas of the brain to help you move. As these substantia nigra nerve cells become sick, they make less dopamine, making movement more difficult over time.

By the time you were diagnosed with Parkinson's, about half of the cells in your substantia nigra were already impaired. Other areas of your brain might have had disease even longer. **So, your Parkinson's has probably been with you for many years.**



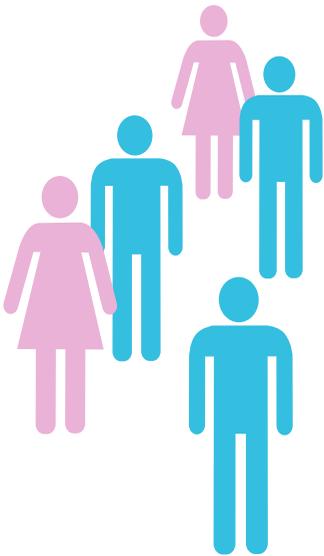
Although we understand a lot about the causes for Parkinson's, the exact cause for the faster aging of the brain in Parkinson's is not known. Parkinson's disease experts have noticed that brain cells affected by Parkinson's, contain an unusually large build-up of a protein (alpha-synuclein). We know that these proteins are important in the development of Parkinson's. However, it is not clear why this build-up happens, and it is not the only factor causing disease.

Who can get Parkinson's?

While we understand a lot about what causes Parkinson's, there is no one simple cause for Parkinson's disease. Quite the opposite, Parkinson's is most often the result of many things, genes, environment, and pure chance. So, for most people, there is no clear answer to the burning question, "Why me?" We do know a few things that can increase your risk (or chance) of getting the disease. These include:

1. Age

Age is clearly the most important risk factor. About **1 in 400** people aged 60 have Parkinson's. This rises up to **1 in 100** people aged 70, and **1 in 40** people aged 80.

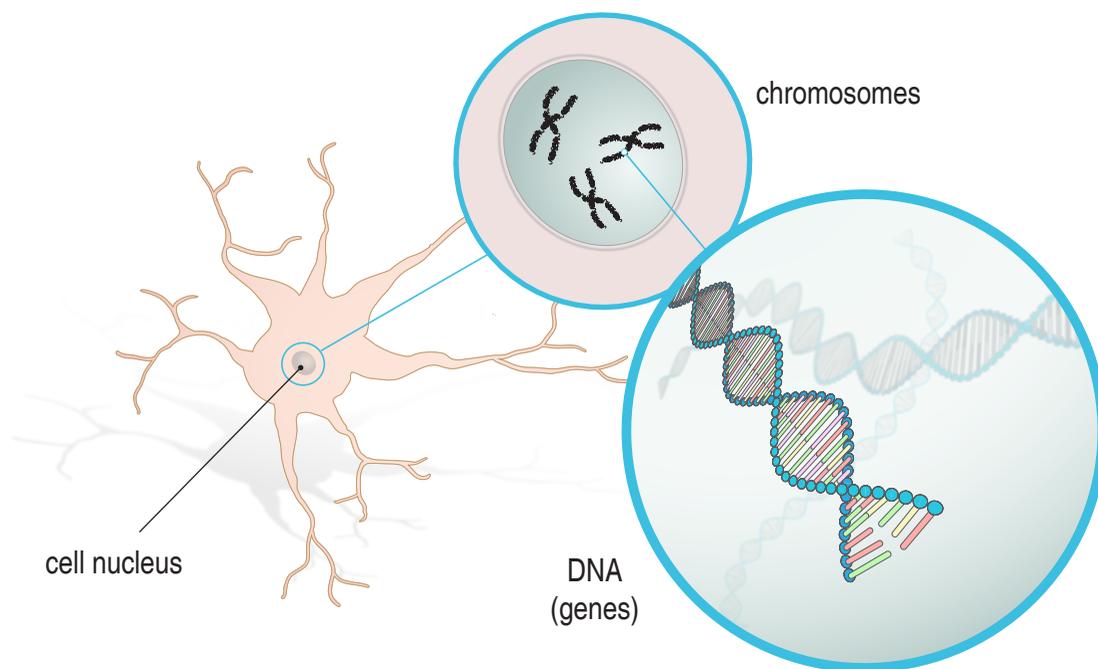


2. Sex

Men are more likely than women to develop Parkinson's disease (about **3 out of 5** Parkinson's patients are men). We do not yet understand why.

3. Genes

Every person carries genes in their body. These genes are passed down through families, from a parent to a child. They decide certain aspects of who you are and what you look like (e.g. your hair color and skin tone.) They help to make you the person that you are.



Genes can also carry the chance of getting certain diseases or health problems. Today, we know that there can be a genetic part to Parkinson's disease. However, very few people have the disease because of just one gene. Instead, for most people, Parkinson's can be caused by a number of things, including genes and the environment. In other words, Parkinson's can "run in families" a bit.

However, this does not mean that your family member will get the illness. To give a rough idea, children of Parkinson's patients have about a double risk of Parkinson's, and brothers and sisters have a triple risk. That sounds like a lot, but remember that Parkinson's is not very common. So, your family member's risk remains quite low.

4.Toxins (chemicals that can damage cells)

Research has shown us that that if a person was exposed to high doses of poisonous chemicals (for example, pesticides), they have more chance of getting Parkinson's disease. For this reason, you are slightly more likely to get Parkinson's disease if you are a farmer or have used well water that may have had trace pesticides in it. Certain industrial solvents may also increase risk. Other chemical toxins may be important, but the full list of toxins that increase Parkinson's risk is not known.



5. Lifestyle

There is no obvious connection between Parkinson's and most lifestyle choices. So, this means there was nothing you did to give you Parkinson's. Interestingly, non-smokers and non-caffeine users have a higher risk of developing Parkinson's; however, it is very unclear why this is. Just because two things are linked does not mean that one caused the other (so don't smoke - it does make some symptoms of Parkinson's worse!!). People who do little exercise may have increased risk as well. Again, it is hard to know why. It could be that exercise prevents Parkinson's, or that very early Parkinson's prevents exercise.

There are some other things that some studies suggest may possibly have increased your chances for the disease. However, we need to do more research to better understand them and know for sure. These possible risk factors usually only act as clues. For most people, there is not one single genetic or environmental 'cause' of their disease.



Did you know?

Parkinson's is not contagious. In other words, you cannot get the illness simply by being in contact with someone who has it.

How we know it's Parkinson's disease (diagnosis)

A neurologist is a doctor who is an expert on the brain and the nervous system. This is usually the person who confirms whether or not you have Parkinson's disease. He or she does this by closely considering the changes you have noticed in your body as well as what he or she finds during your check-up.

Usually, the diagnosis does not depend upon any blood tests, scans, etc. Sometimes, your doctor may order some more tests to be sure that this is not a "Parkinson's look-alike". However, most of the time, no further tests are ordered.

Most of the time, people with the motor changes called 'parkinsonism' have Parkinson's disease as the cause. However, there are some other conditions that can be Parkinson's look-alikes. These include:



Other aging nerve cell diseases

There are several nerve-aging diseases that also cause 'parkinsonism'. Most of these diseases (e.g. multiple system atrophy, progressive supranuclear palsy, corticobasal degeneration) are more serious than Parkinson's disease.

People with these illnesses will have more severe movement problems. Treatment will not work as well for them.

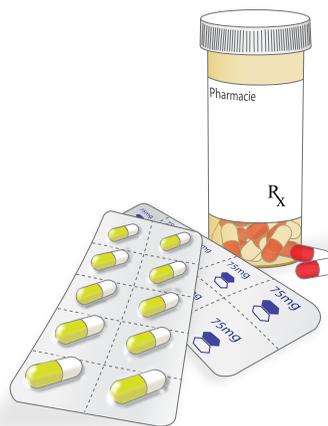
Early on, these diseases may look like Parkinson's disease. However, after several years, it will become clearer that this is something different.

Most of these illnesses are treated in the same general way as Parkinson's. For this reason, any delay in identifying them would not have greatly changed the treatment you received.

Medications

Some medications can lead to changes that look like Parkinson's disease. Examples include medications used for psychiatric problems (e.g. for schizophrenia), nausea, and rarely some medications for high blood pressure.

Ask your doctor or pharmacist if the medications you are taking can cause changes that look like Parkinson's disease



Some tremor conditions

Some tremor conditions (e.g. essential tremor, dystonic tremor) can look like Parkinson's disease. However, people with these problems usually don't have true rigidity or slowing of movement.

Overall, on the first visit, a diagnosis of Parkinson's is 'right' most of time. After diagnosis, however, your doctor will still check very closely how your body responds to treatment. They will continue to watch out for signs of other illnesses. As time goes by, they will be more and more certain that your diagnosis is right.

Treatments for Parkinson's

What you should know about treatment

Treatment of Parkinson's is very complex, and cannot be easily summarized. Parts 2 and 3 contain a lot of detail; go to these sections to find more complete information. For now, there are a few essential points to consider:



1. Treatment helps you feel better but doesn't stop the aging

There are no treatments available today that clearly stop or slow down the cell aging we see in Parkinson's disease. This may, however, change in the future, because this is the topic that is most studied and researched by Parkinson's experts today. As a result of this research, there are a number of promising possibilities for the future. So, stay hopeful!

2. Everyone is different

Every Parkinson's patient is unique. For this reason, there is no 'one-size-fits-all' treatment for Parkinson's disease. Together, you and your doctor together will find the combination of medications that work best for you.

3. Parkinson's changes over time

As the disease changes over time, so will your treatment. Most of the time, we will be constantly 'tinkering' with your medications. We will always try to find the best combination that works for you right now.

4. You can't 'save' medications for later

Because Parkinson's changes over time, it can sometimes look like the medications work less with time. So it's natural to think you should reserve them for when you really need them. However, this is not true. The good news is that we now have medications that work in both early and late stages of the disease. For this reason, use whatever treatments you need to function well in your daily life. If anything, waiting too long is more likely to be harmful than starting early.



5. Side effects are to be balanced, not feared

The goal of treatment is to make you feel better and improve your quality of life. Any treatment has potential side effects, which some people get and others don't. Sometimes the side effects go away with time. Other times they stay but are mild. You might feel so much better in general, that you will prefer to put up with the side effects rather than stop treatment. The good news is that essentially all bothersome side effects quickly go away if the medication is stopped. So, you don't have to fear them in advance. Discuss any problems with your health care team, and they can help you find the right balance.

Did you know?

Dopamine treatments can work very well. In the first few years of the disease, most people taking dopamine are able to move normally again and manage day-to-day life without much trouble.

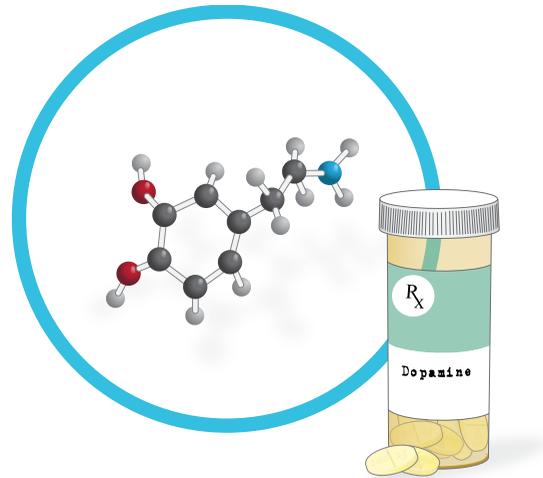
What are the treatments?

There are a number of treatments available today for Parkinson's disease. These include:

1. Treatment for body movement (motor) problems

Dopamine is the best treatment we have today for Parkinson's disease. Here's why. At the base of your brain, there is an area called the substantia nigra. This area is an important control centre for body movement.

The cells in the substantia nigra release a chemical called dopamine. Dopamine sends messages from the brain to other parts of the body to help you move. As your nerve cells become sick, your body will make less dopamine, and so you move less well.



So, the key treatment for Parkinson's disease is to replace the dopamine that you are missing. There are different ways to do this. The most common options are:

Levodopa

The most direct and effective way is to simply take dopamine. (You may sometimes hear it called Sinemet®, Prolopa®, or Madopar® (Madopar is used outside of North America)).

Other common treatments include:

Medications that act like dopamine (called dopamine agonists)

Medications that keep dopamine from breaking down in your brain (called MAO-inhibitors, COMT-inhibitors).

It is important to know that each of these medications acts differently. They can also all have some unwanted reactions (side effects). Your doctor will keep these things in mind. He or she will tailor your treatment so that it works in the best way possible for you.

2. Treatments for other (non-motor) changes in your body

Parkinson's disease can bring with it many different kinds of non-motor changes. The good news is that they can often be treated quite well. Many of these may have started before any movement changes, so you did not realize the connection. Scan the table of contents in the non-motor section (Part 3) of this guide to find problems that you are experiencing, and then read about those specific areas.



3. Non-medication treatments: healthy living

There are some things that you can do (besides taking your medications) to live well with Parkinson's disease. These healthy life choices can help you feel better, and may improve the overall course of your disease. Probably the most important of these is exercise. We know that exercise can make you feel better and improve your overall health. There are also some studies that suggest it can help treat Parkinson's specifically.

Try to stay active in any way that works best for you. Exercise every day if you can. Whenever possible, push yourself hard enough to sweat a little. Speak to your doctor before starting a major new activity or if you have questions and concerns. There are no special eating plans for people with Parkinson's disease. Instead, we recommend that you eat a healthy and balanced diet

There are also many other specialists who are also here to help:

Specialized nurses are part of many Parkinson clinics. They can help you navigate clinic or community resources, and can be the first line providers of teaching and troubleshooting for any problems that arise.

- Physiotherapists can help you with balance and movement.
- Occupational therapists can offer you tips and find equipment to help you cope at home.
- Speech therapists can help with voice and swallowing.
- Nutritionists can help you with healthy eating and if needed, special diets.



Social workers can provide supportive counseling, help with issues around work and finance, and help you connect with community and government resources.

Did you know?

While non-medication treatments can play an important part in your health and well-being, they alone are not enough. It is very important to take your medications, as your doctor has explained.

Take an active part in your care

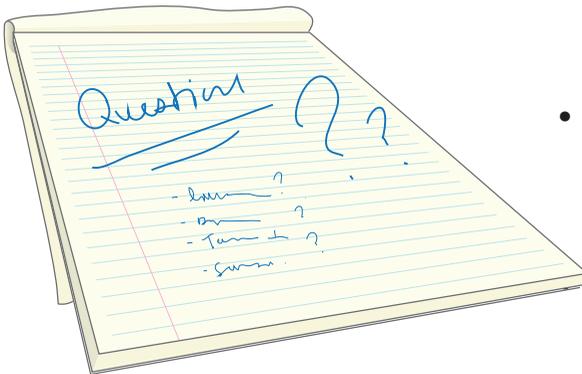
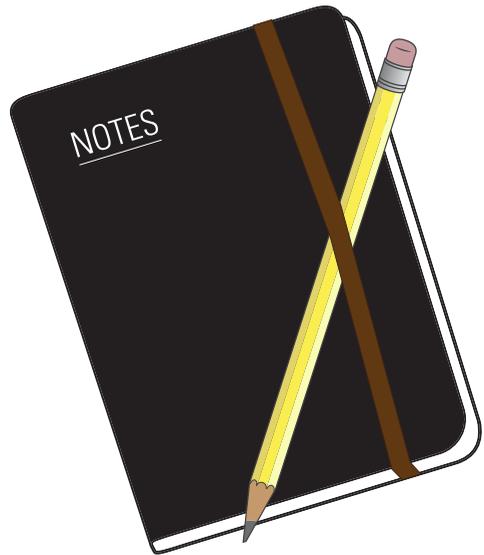
We know that this is a difficult time for you and your family. You may feel as if much is out of your control. However, there is a lot that you can do manage your care as an active member of your care team. Together, we want to help you live life to the fullest.

This guide should help you stay informed about Parkinson's in general. However, this is only where it starts. To take an active part in your care:



- Embrace healthy living. Eat a healthy, balanced diet and exercise as much as you can.
- Take your medications, as they were explained by your doctor. If they are causing side effects, telephone your health care team to ask if things should change.

- Keep track of any changes you notice in your body. Pay attention to the timing of your symptoms, as it will help your health care team plan your treatment better.
- Be prepared for your clinic visits. Your appointments will be about 15 to 30 minutes long. You want to make the best use of this time. Come prepared with questions and concerns that you would like to discuss. Write these things down before your visit. This way, you can be sure that you discuss your most important concerns
- Write things down also immediately after your visit. This way, you can remember what was discussed.



- Help your health care team prioritize where you can. Tell them what changes are causing the most trouble in your life right now. This will help your team arrange your treatments in the way that would best meet your needs.
 - See the 'Frequently-asked questions' section (**page 116**) of this guide for more advice on how to prepare for medical visits.
- Ask questions. Seek out more information if you need it.

This ends the 'basics' section of the book. You may wish to stop here. More information on motor Parkinson's is in Part II. Information on non-motor Parkinson's is in Part III. You can also scan the 'frequently asked questions' section at the back if there are specific questions that haven't been answered.

Part 2 Motor Symptoms:

Changes in how you move

What are the motor symptoms of Parkinson's disease?

- Slow movement (bradykinesia)
- Shaking (rest tremor)
- Stiffness (rigidity)
- Balance problems
- Freezing episodes (freezing of gait)

What are the treatments?

- Dopamine (Levodopa)
- Dopamine agonists (Dopamine copycats)

Other medications that affect dopamine

- MAO - inhibitors
- COMT- inhibitors

Other medications for motor symptoms

- Amantadine
- Anticholinergic medications

Special therapies for Advanced Parkinson's

- Deep brain stimulation
- Continuous medication delivery

What are the motor symptoms of Parkinson's disease?

Parkinson's is a disease that is constantly changing. It is chronic (lasting many years) and progressive (worsens over time). As there is currently no cure for Parkinson's, the goal of treatment is to keep your symptoms in check.

Through it all, you and your Parkinson's care team will work together to continuously define and redefine the best treatment plan for you.

There is no 'one-size-fits-all' treatment for Parkinson's. Just as no 2 patients are alike; no 2 moments in your disease will be the same. You may notice some symptoms early on, while others appear later. As your Parkinson's changes, our treatment will need to change with it.

The good news is that Parkinson's treatments for motor symptoms can be extremely effective. Most people with Parkinson's live a full and productive life for many years.

Slow movement (bradykinesia)

What is this?

Bradykinesia refers to movements becoming slower and smaller. It is felt by many with Parkinson's as the most bothersome motor symptom of the disease.



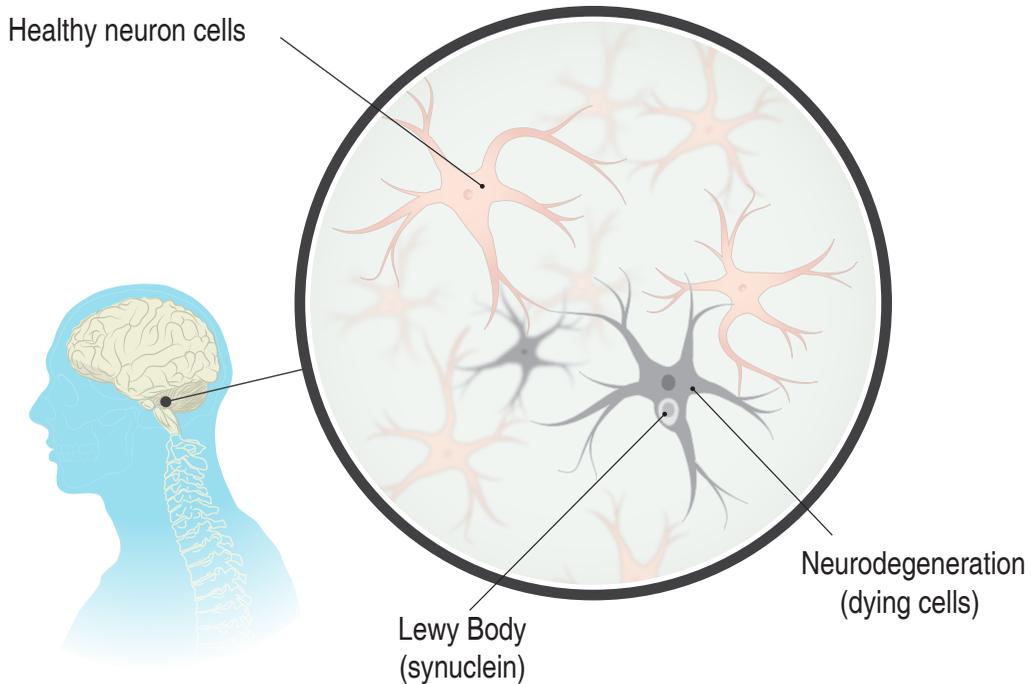
This slowing down of movement may feel like weakness, but you are not becoming weaker. Instead, you are having difficulty starting and maintaining a movement. Bradykinesia affects all movements. Examples are:

- You have trouble with tasks that have repetitive movements (e.g. buttoning a shirt, brushing teeth or cutting food).
- Your handwriting becomes smaller, especially towards the end of a sentence.
- You start speaking at normal volume but then, your voice starts to trail off at the end of a phrase.
- You walk more slowly. You shuffle or take smaller steps.
- Your most affected leg seems to drag.
- Your face is less expressive, (known as “masked face”). You may look less happy or enthusiastic. Family or friends sometimes falsely interpret this as depression.

In most people, this change starts on one side of the body, and then later spreads to the other side. As this happens gradually, you may not be aware of all these changes.

Why does this happen?

Slower and smaller movements are related to lowering levels of **dopamine** (the chemical in your body that controls movement). In Parkinson's, some of the nerve cells that make dopamine in the brain are dying (**nerve cell degeneration**). Without dopamine in these key areas, your brain is essentially sending out a "Don't move" message to the rest of your body.



What can I do?

Stay active and keep a regular exercise routine. This will help you better cope with the slowing down of movement. It may even help you overcome it to an extent. Always be open to exploring new ways to cope. This will help you maintain a full and productive life.

What are my treatment options?

There is good news! Bradykinesia is very well managed with dopamine medications. (**see page 35** for more details). Exercise, speech therapy training and physiotherapy can also make a difference.

Key points

- * Bradykinesia refers to movements becoming slower and smaller. It is seen by many with Parkinson's as the most bothersome motor symptom of the disease.
- * This slowing down affects all movements.
- * As it tends to start gradually, you may not notice many changes yourself.
- * Bradykinesia is very well managed with treatment, such as dopamine medication, speech therapy training, and exercise.



Shaking (rest tremor)

What is this?

Resting tremor refers to shaking or trembling of the hand, foot, or jaw. This tremor tends to appear while you are seated with hands on your lap or or while they are resting loosely at you side. It usually stops when you start moving, although, some people may have tremor while they are moving as well.

You may notice that tremor re-appears if you stay in the same position for a long time. Also, tremor is usually more obvious on one side of the body. (However, it can spread to the other side.)



While this is the most noticeable sign of Parkinson's disease, not all people with Parkinson's experience tremor. Tremors are seen in only 2 out of 3 people with Parkinson's. (In other words, you can still have Parkinson's if you do not have tremor.) Finally, tremor does not necessarily worsen as the disease evolves.

Why does this happen?

Just as with the other motor problems seen in Parkinson's, tremor is due to the loss of **dopamine** in your body (caused by dying **nerve cells**). That said, the exact connection between tremor and dopamine is not very straightforward. For this reason, tremor is **not** a sign of whether your medications are or are not working. In other words, you may still notice some tremor, even if your other symptoms are well controlled by your medications.

What can I do?

Tremor can temporarily worsen during periods of anxiety, stress and fatigue. So, relaxation strategies can help.



Did you know?

Having some tremor does not mean that your medications need to be changed. If you are wondering whether your medications are making a difference, keep track of how the speed or ease of your movements is improving. This is a better sign of whether your medications are working.

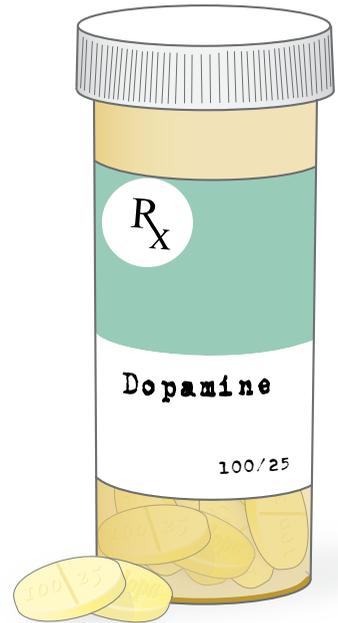
What are my treatment options?

Most people see tremor as an annoyance, more than a disability. That said, if your tremor makes everyday activities difficult (e.g. eating, getting ready), speak to your doctor. Tremors can be managed with treatment. Your doctor may suggest:

Dopamine medication – These medications work by replacing dopamine in your body. They are the main treatment for tremor.

Anticholinergic medication - This is used if dopamine medication does not help. As this group of medications has many side effects (e.g. memory problems), they are generally only offered to younger people. (see page 58 to learn more)

Surgery - Sometimes, severe tremor is treated in surgery using a technique called “deep brain stimulation”. This is generally reserved for people with advanced Parkinson’s. (see page 59 to learn more)



- * Resting tremor refers to shaking or trembling of the hand, foot, or jaw.
- * This is often the most noticeable symptom of Parkinson’s disease.
- * It often starts on one side of the body
- * More than 1 out of 3 people with Parkinson’s do not have tremor.
- * Dopamine medications are the main treatment, although relaxing strategies or other medications can help as well.

Stiffness (rigidity)

What is this?

Rigidity or stiffness refers to a lack of flexibility in the muscles of your arms, legs, trunk (torso) or neck. You might not necessarily be aware of this stiffness, but your doctor will detect this during your check-up.

If you do notice it, rigidity can feel like tightness of the neck, shoulder, wrist, elbow or leg. You may also feel it more on one side of your body. At times, this stiffness may cause muscle aching.

Why does this happen?

Muscles contract during movement, and relax when at rest. In Parkinson's disease, the muscles do not properly relax when you are at rest. This is also related to the loss of dopamine in your brain.



What can I do?

Stretching exercises, massage and relaxation therapy can ease this symptom a bit. However, medications are the main treatment.

What are my treatment options?

Dopamine medication is the main treatment option for this motor symptom. Your doctor may adjust how much you are taking (dose), if you have cramping or pain from time to time. Your doctor may also suggest over-the-counter pain medication (e.g. **acetaminophen, ibuprofen**). These medications can be taken as you continue your stretching exercises.



Key points

- * Rigidity refers to stiffness or lack of flexibility in your arms, legs, trunk (torso) or neck.
- * The main treatment for rigidity is dopamine medication, and sometimes, acetaminophen and/or ibuprofen.
- * Stretching, massage, relaxation exercises and physiotherapy can help.

Balance problems

What is this?

This motor symptom refers to being unstable when standing upright. Difficulty with balance often occurs when you are changing position (e.g. rising from a chair or making a turn.) During early Parkinson's, you may notice **mild** balance problems (e.g. stumbling to the side). During later stages of Parkinson's, balance problems can increase your chances of having a fall.

What can I do?

Balance training is the most important treatment for balance problems. This could include:

- Tai chi, yoga or dance
- Strength-building exercises of your trunk (or torso) muscles
- Aerobic exercises (e.g. bicycling, swimming, water aerobics)

Your physiotherapist can guide you on what might work best for you. He or she may also suggest specific training exercises.

Why does this happen?

With Parkinson's disease, the reflexes needed to keep your balance are not as strong. This is again due to dying nerve cells (**nerve cell degeneration**) which affects balance control centres in the brain. These include dopamine areas, but also involve other areas of the brain (which is why dopamine treatment is not always as helpful).



Take measures to prevent falls.

While the use of walking aids, such as walkers and canes, can make a big difference, there are many other things you can do. Speak to your health care professional to learn more.

What are my treatment options?

There is no specific treatment for balance problems. Dopamine medication can help if balance problems are related to slow movement of your legs.



Key points

- * Difficulty with balance refers to being unstable when standing upright. This can lead to stumbling, walking problems and falls.
- * Walking aids (cane, walker, wheelchair) can make a big difference. Balance training, such as strength-building exercises, tai chi and dance can help.
- * Taking measures to prevent falls during later stages of the disease is very important.
- * Speak to your physiotherapist if you have questions or concerns. He or she can help.

Freezing episodes (freezing of gait)

What is this?

A freezing episode refers to the situation where a person with Parkinson's **feels as if their feet are glued to the floor while trying to walk**. This often happens when starting to walk, while crossing a doorway, going around furniture, or making a turn. Freezing usually lasts for a few seconds and disappears once the person makes the first step.

Somewhat related to freezing, **you may also experience festination**. This is the tendency to take small, hurried steps, while leaning forward. As this happens, you may feel as though your feet are not able to catch up to your body.

Freezing episodes and festination can lead to falls.



Why does this happen?

Freezing often happens during later stages of the disease. It is caused by nerve cells dying in both dopamine centers and other areas of the brain. As a result, you no longer have the internal cues you need for walking.

What can I do?

There are a number of things you can try to get around a freezing episode:

- **Avoid multi-tasking** while walking. Doing only one thing at a time can lower your chances of a freezing episode or fall.
- **Use visual cues.** Patterns or simple lines on the floor can help.
- **Focus your eyes on a target** (visual cue). Ask someone near you to help by placing a target in front of you. For instance, ask them to put their foot in front of you. Then, try stepping over it.
- **Listen to a rhythmic sound** (auditory cue). For instance, play music through your headphones as you walk.

What are my treatment options?

Freezing is often difficult to treat. Dopamine medications can sometimes help freezing, especially if you notice that freezing happens when the medications are wearing off (during **off times**.) We call these episodes **motor fluctuations**. (see **page 48** to learn more)

Pay careful attention to when freezing occurs. If you notice it during **off times**, then adjusting **when** you take your medications can make a difference. Some small studies have also suggested that medications that make you more alert (e.g. Ritalin) or amantadine may help a small amount. Speak to your doctor before making any changes to your medications or if you have questions.

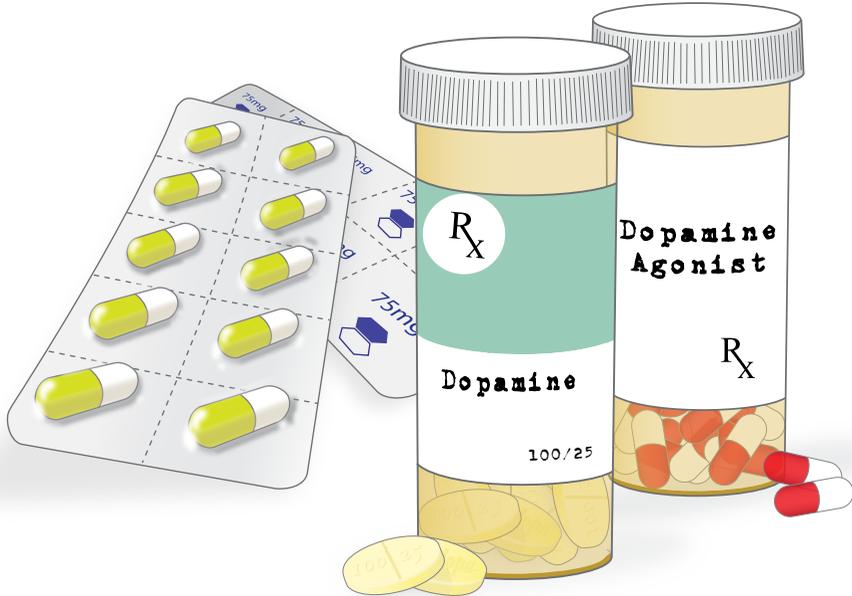


- * During a freezing episode, people with Parkinson's feel their feet are "glued" to the floor while trying to walk.
- * Freezing can lead to falls
- * Avoid multi-tasking when walking. Focus your eyes on a target or listen to a rhythmic sound as you walk. These strategies can help you get around a freezing episode.
- * Dopamine medication can sometimes help.

What are the treatments?

There are 3 main types of dopamine medications used in Parkinson's. These medications all essentially work to raise dopamine levels in your brain. They include:

1. **Dopamine itself** -This medication is called levodopa.
2. **Dopamine copycats** – These are also called dopamine-agonist medications.
3. **Other medications** that help keep dopamine in the brain for a longer period of time - We call these MAO-inhibitors and COMT-inhibitors.



In addition to dopamine, there are medications that are used in Parkinson's to handle **special situations** (e.g. amantadine, anticholinergic medications).

During late stages of Parkinson's, your treatment team may suggest surgery (**see page 59** to learn more). During these later years, the focus of your treatment will be on combining different medications and adjusting your medication **dose**.

Parkinson's is a disease that is constantly changing. It is chronic (lasting many years) and **progressive** (worsens over time). As there is currently no cure for Parkinson's, the goal of treatment is to keep your symptoms in check.

There is no 'one-size-fits-all' treatment for Parkinson's. Just as no 2 patients are alike; no 2 moments in your disease will be the same. You may notice some symptoms early on, while others appear later. Still others may occur at any time during the course of the disease. As your Parkinson's changes, our treatment will need to change with it.



The good news is that Parkinson's treatments for motor symptoms can be extremely effective. Most people with Parkinson's live a full and productive life for many years. Through it all, you and your Parkinson's care team will work together to continuously define and redefine the best treatment plan for you.

Dopamine (Levodopa)

What is it?

Levodopa, or **L-dopa**, is the main and most effective treatment for Parkinson's disease. While it is found naturally in a number of plants, for Parkinson's patients, levodopa comes in pill form.

When swallowed, levodopa is broken down and absorbed in the stomach. This causes lots of nausea and allows only small amounts of the medication to make it to the brain. For this reason, another substance called, carbidopa (or benserazide), is added to levodopa. Carbidopa helps levodopa reach the brain by keeping it from being broken down in your stomach. In doing so, it also works to lower nausea.

Unlike regular dopamine, levodopa is the 'levo' form of dopamine. Your blood carries this form of dopamine from your blood, straight into your brain. Once in the brain, your body changes levodopa to natural dopamine.



The most common types of levodopa that are available in North America are:

- Levodopa/Carbidopa (sometimes called Sinemet)
- Levodopa/Benserazide (sometimes called Prolopa)
- Slow-release Levodopa (Sinemet CR). This form of the medication lasts a little longer, but often needs to be taken in larger doses for the same effect.

Other forms of levodopa, which may have longer-lasting effects, are also now being developed.

Did you know?

Your levodopa preparation will contain 2 numbers (e.g. 100/25):

- The first is the levodopa dose (the most important one to remember).
- The second is the carbidopa dose.

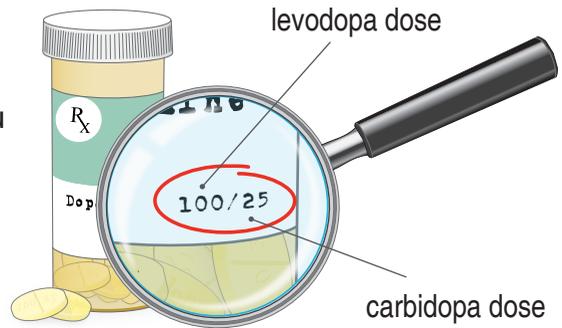
What does it do?

Levodopa will help anyone with Parkinson's disease. (If there is no improvement with this medication, you may not have Parkinson's disease).

This medication helps with:

- slowness (**bradykinesia**)
- stiffness (**rigidity**)
- shaking (**tremor**) – only for some people

It is less likely to help with poor balance, falls and many **non-motor** problems (**see page 65**). This medication will extend the period of time that most people can lead a relatively full and productive life.

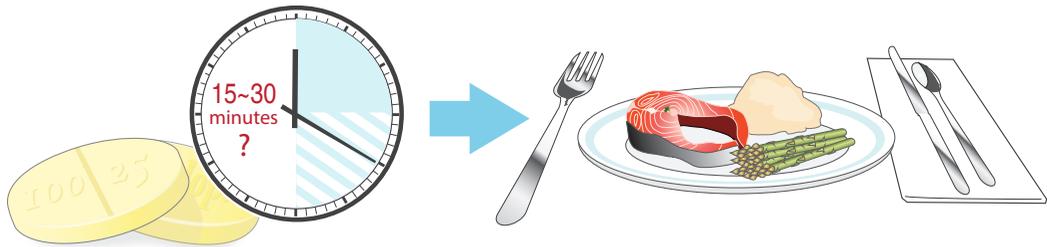


How should I take this?

High-protein meals can limit how much of this medication is absorbed in your stomach. Levodopa is best absorbed on an empty stomach before your meal, ideally 15 to 30 minutes ahead. However, most patients can take it at the same time as their meals; just make sure the pills get taken before the food.

Taking your medication 1 hour or so earlier or later is not a problem during early Parkinson's. If you miss a dose, simply take your levodopa as soon as you remember. In late Parkinson's, you may notice that timing becomes important. You may feel unwell (or 'off') when you are late.

Your doctor will usually start you on a low dose of levodopa. (This is usually around 1-2 pills, taken 3 times per day). Over time, as the disease progresses, your doctor will suggest you take a stronger dose, or that you take your pills more often. There is no clear maximum dose. You and your doctor will work together to find the dose that works best for you. Your dose will be one that best controls your symptoms and has the least amount of side effects (unwanted reactions).



How quickly will it work?

You should notice your motor symptoms improve within days of taking levodopa. This benefit can build up over a few months.

What are the common side effects (unwanted reactions)?

Levodopa has most of the same side effects as the other medications used for Parkinson's.



Nausea, stomach upset and low blood pressure – These most common side effects are due to dopamine's effect on your stomach, intestines and blood vessels.

Side effects usually go away on their own. If they do not, your doctor may suggest you take **domperidone** medication. (This is not available in some countries).



Sleepiness (or drowsiness) – People usually experience sleepiness 1 to 2 hours after taking their medication. If you notice this, avoid driving, drinking alcohol, or operating heavy machinery. These activities can be dangerous if you are drowsy. Speak to your doctor. He or she may need to adjust your medication.



Hallucinations (seeing things that aren't really there) – This is a problem in later stages of the disease (see page 105).

The good news is that hallucinations can be controlled and will generally go away when we lower your dose (the amount of medication you take).

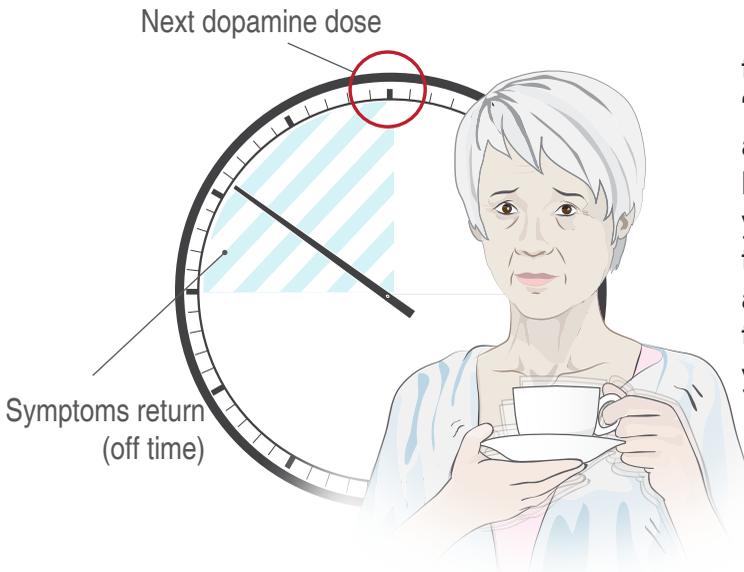
Did you know?

Domperidone blocks any side effects that levodopa might have outside the brain. At the same time, it does not change how levodopa works in the brain.

Domperidone itself does not have many side effects. However, if you are taking a strong dose (e.g. more than 1 pill, 3 times a day), it can cause irregular heartbeat problems. For this reason, once your nausea or blood pressure is better, your doctor may ask you to only take 1 or 2 pills each day.

The rise and fall of levodopa's effects (motor fluctuations)

As time goes on, you may begin to notice periods of the day when your medication is working less well ("off" times). Younger people and those who find their medication is working very well may notice this more. Most of the time, "off" times start up just minutes to hours before your next dose is due.



You may feel as though the Parkinson's has "come back". Off periods are related to how long levodopa's effect lasts in your body. As this period of time keeps changing, you and your doctor will need to work together to change your treatment approach.

If you notice on and off periods

1. Keep careful track of when this happens. If you understand your pattern, it will be easier for your doctor to offer you options to adjust your treatments. If it is hard to remember, use a diary to keep track of:

- how long exactly it takes for your medication to wear off
- how long it takes for the next one to kick in
- any other changes or patterns that happen during the day



2. Speak to your doctor. He or she will need to adjust your medication dose (how much you are taking). To do this, your doctor may explore a number of different options with you (e.g. changing how often you take your medication and/or adding new longer-acting medication).

Did you know?

Many Parkinson's disease organizations offer special diaries to help you keep track of Parkinson symptoms? Speak to a member of your treatment team or contact your local Parkinson's society, if you are interested in this resource.

Increased movements (dyskinesia)

What is this?

Some people may notice increased movements, such as twisting, twitching, and writhing. These movements are called **dyskinesia**. They usually appear about 1 to 2 hours after you have taken your medication. Less often, people notice this as their medication is wearing off.

Dyskinesia is usually not bothersome. You may not even be aware that you have this. More serious dyskinesia, however, can be tiring. It can meddle with your other movements, or, even make you lose balance. Speak to your health care team if you are having trouble with dyskinesia.

Why does this happen?

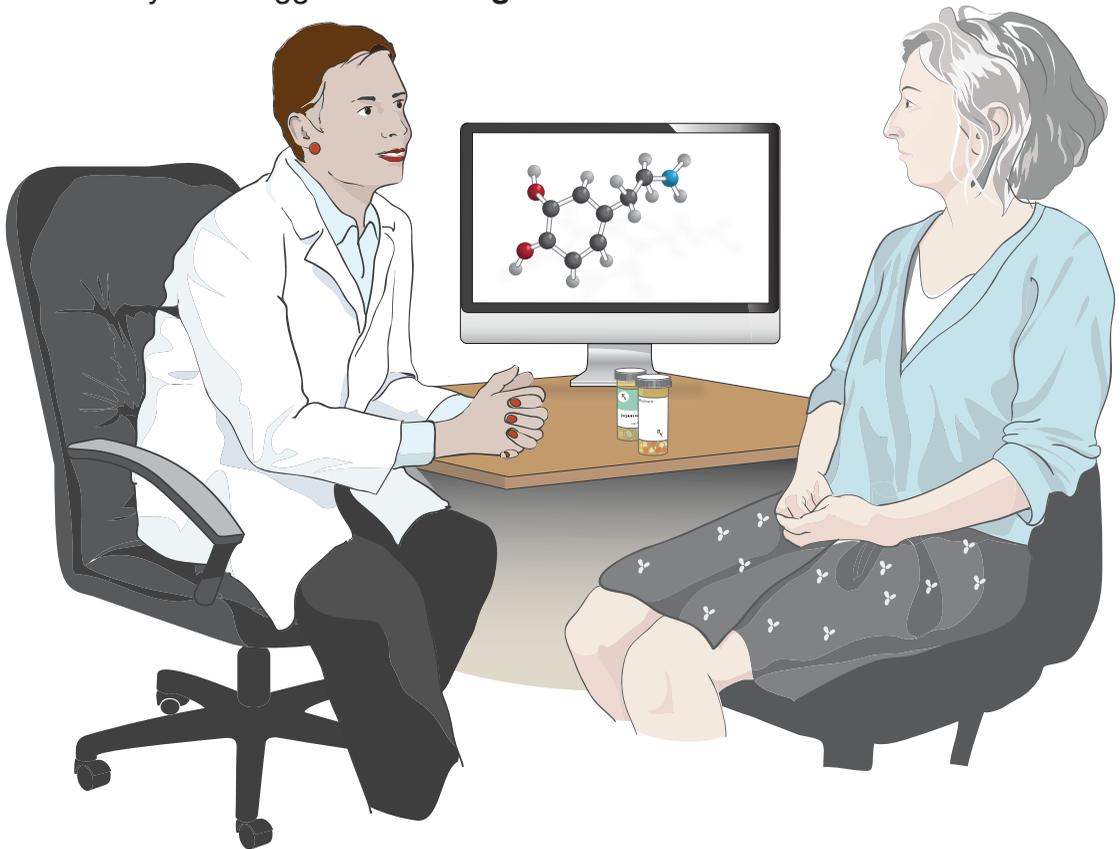
Dyskinesia is a sign that your medication is working, but perhaps a bit too well. **All Parkinson's medications can cause increased movements**, but since levodopa is the most effective medication, it tends to cause this the most. Also, people taking large doses of their medication tend to have this more often.



What are my treatment options?

A lower medication dose should help keep your dyskinesia in check. However, this can end up bringing back the “off” periods as well as the other motor problems you used to have. For this reason, your dose may need more careful fine-tuning. Your doctor may also suggest other **long-**

acting medications while reducing the levodopa. These medications are slower to start-up, but once they do, their effect will last longer in your body. **Amantadine** is another medication that can also help (**see page 57** to learn more).



Treatment options: Dopamine

Levodopa is the main medication for Parkinson’s. There are other medications that are helpful. However, they are usually not strong enough to treat Parkinson’s for more than 2 or 3 years on their own. For this reason, you will often take the other medications together **with** your levodopa. The next section will describe these in more detail.

Dopamine agonists (Dopamine copycats)

What is this?

Dopamine copycats (or **dopamine agonists**) are medications that act like dopamine in the brain. These medications do not work as well as levodopa in controlling Parkinson's symptoms. However, they do have a more stable, and long-lasting effect.

What does it do?

Dopamine copycats will help relieve the same motor symptoms as levodopa. (**See page 52**).

What are the common side effects?

Dopamine copycat medications have the same side effects as levodopa. These include:



How should I take this?

Examples of this type of medication are pramipexole, ropinirole, and rotigotine. Pramipexole and ropinirole are pills. These are usually taken 3 times each day. Rotigotine is a patch that can be placed on your stomach, thigh or arm 1 time each day. Your skin will absorb the medication from the patch.



hallucinations - (seeing things that are not really there)

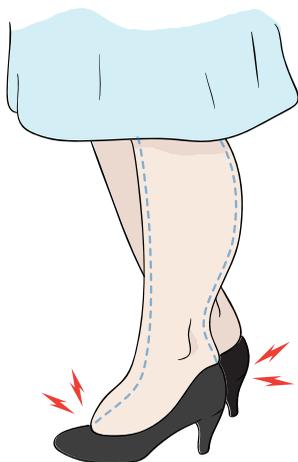


nausea



drowsiness

sleep attacks – This refers to intense sleepiness that can come on so quickly that you may fall asleep with no warning. As this could happen while eating, standing, speaking, or driving, it can be dangerous. If you notice serious daytime sleepiness, speak to your doctor right away.



leg swelling

These side effects tend to happen more with dopamine copycats than with levodopa. However, **dyskinesia** (increased movements) and the **wearing-off effect** happen less with dopamine copycat medications. This is because they do not work as well as levodopa and due to their longer-lasting effect.

Did you know?

It is also important to keep a watch out for one other possible side effect: some people may develop **strong urges that are hard to control**.

This could include uncontrollable desires to gamble, shop, or have sex. This can sometimes cause serious problems. As with all side effects, it will go away quickly when you stop the medication. As you might not notice this problem yourself, make sure your family or caregivers are aware that this could happen. Ask them for their help in watching for it.

Other medications that affect dopamine

(MAO and COMT-inhibitors)

What is this?

Your doctor may discuss another group of medications with you. These help to keep dopamine in your body for a longer period of time. They do this by slowing how your body breaks dopamine down. There are 2 types of medications that have this effect on dopamine:

MAO-inhibitors - These medications keep natural dopamine in your brain.

COMT-inhibitors – These medications help levodopa last longer.

MAO-inhibitors

(e.g. selegiline, rasagiline)



Why does it do

These medications slow down **MAO-B**, a substance in your body which breaks dopamine down in your brain. Some research seems to suggest that this group of medications could slow down the disease process itself. However, more studies are needed here, as the evidence for this is not strong.

MAO-inhibitors generally have a relatively mild, but long-lasting effect. In other words, you are not likely to notice them wearing off.

How should I take this?

Selegiline is taken 2 times a day (usually in the morning and at noon/afternoon). **Rasagiline** (or **Azilect**) is taken 1 time each day.

What are the common side effects?

MAO-inhibitors generally have few side effects. You may notice:



trouble falling asleep
(especially if taken in the late afternoon or evening.)



headaches



nausea

Did you know?

In *rare* instances, MAO-inhibitor medications may raise your blood pressure when taken with:

- foods that contain extremely high amounts of tyramine. (This is found in cured meats, aged cheeses, and wine, to name a few.)
- other medications, such as depression medication (anti-depressants). Tell your doctor about any depression medications you might be taking.

Your pharmacist may be cautious however, this effect is extremely rare. For this reason, as long as your doctor agrees, you should be able to take MAO-inhibitors with your antidepressant medications. You also do not need to avoid these foods.

COMT-Inhibitors (e.g. entacapone)

Why does it do

COMT-inhibitor medications slow down **COMT**, a substance in your body which breaks dopamine down in your brain. Your doctor will usually only offer you this medication if you are experiencing **off periods**. For example, entacapone can increase your 'on' time by about 1 hour a day.

How should I take this?

Entacapone has no effect on Parkinson's when taken alone. This is because it only works on levodopa. For this reason, it is usually given with levodopa, either as a separate pill (e.g. **Comtan**), or in a levodopa-combination pill (e.g. **Stalevo**).

What are the common side effects?

The side effects for COMT-inhibitor medications are exactly the same as when you are taking higher doses of levodopa. You may notice **dyskinesia** or **nausea**. (see page 47 to learn more). This medication can also sometimes cause **diarrhea**.

Entacapone may also make your urine a brownish-orange colour. This is harmless.



nausea



dyskinesia

Other medications for motor symptoms

Amantadine

What is this?

Amantadine is a medication that is used to treat movement problems. It is especially used for increased movement (**dyskinesia**).

How should I take this?

If your doctor suggests this medication for you, you will need to take it 2 to 3 times a day.

What are the common side effects?

The side effects of this medication are similar to dopamine medications. The most common are:

Why does it do?

Amantadine is mainly used for **dyskinesia** (increased movements, **see page 50** to learn more). For some people, amantadine can relieve this problem quite well, without bringing back other motor symptoms. Amantadine generally has less of an effect on slow movement and tremor. However, as it may help with **fatigue in some people**.



livedo reticularis

- **nausea**
- **hallucinations** : (For this reason, your doctor may suggest you avoid taking it in the evening, when hallucinations tend to happen).
- **livedo reticularis** : Amantadine can also cause this a bluish lace-like color change that can appear over the calves of your legs. It can look a bit odd, however, it is harmless.

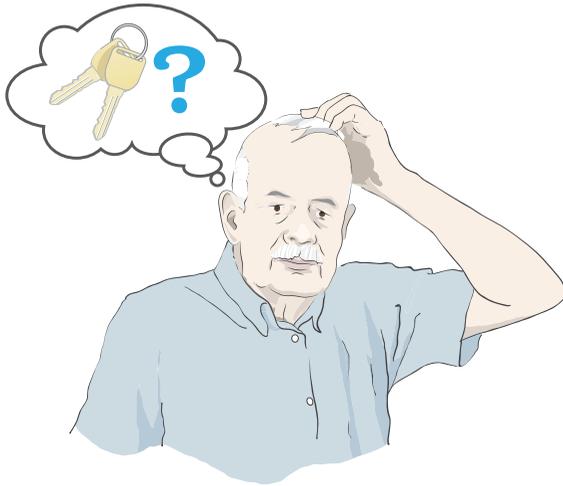
Anticholinergic medications

Why is this?

Anticholinergic medications are sometimes used to control Parkinson's motor symptoms. For unclear reasons, they seem to work best on tremor. The most common of these medications are trihexyphenidyl (**Artane**) or bethropine (**Cogentin**).

What are the common side effects?

These medications can have a lot of side effects. The most common are:



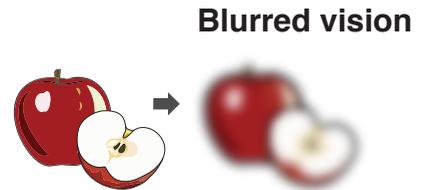
- * **Memory loss** - this is the most important side effect of these medications. This happens more often in older people. For this reason, your doctor might only suggest this medication if you are under 50 years old.

Why does it do?

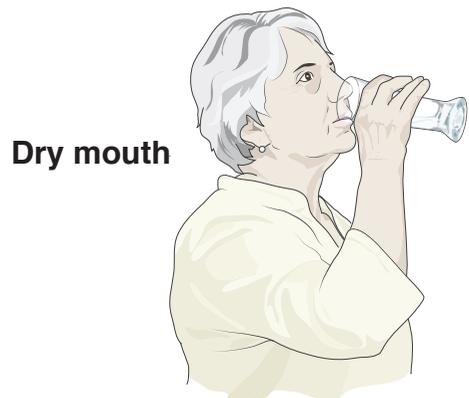
Anticholinergic medications lower the amount of **acetylcholine** (a chemical that sends messages from your nerves to your muscles) in your brain.



Constipation



Blurred vision



Dry mouth

These side effects can be managed and controlled. Speak to your health care team if you notice any or have concerns and questions.

Please also keep in mind that your doctor will consider many other medications in order to manage the non-motor symptoms of Parkinson's disease. These symptoms and their treatments are described in Section 3 of this guide.

Special therapies for Advanced Parkinson's

After you have had Parkinson's for many years, your doctor may suggest other treatment options. These special therapies are not considered for people at early stages of the disease. **For this reason, if you have early Parkinson's, you might wish to skip this section.**

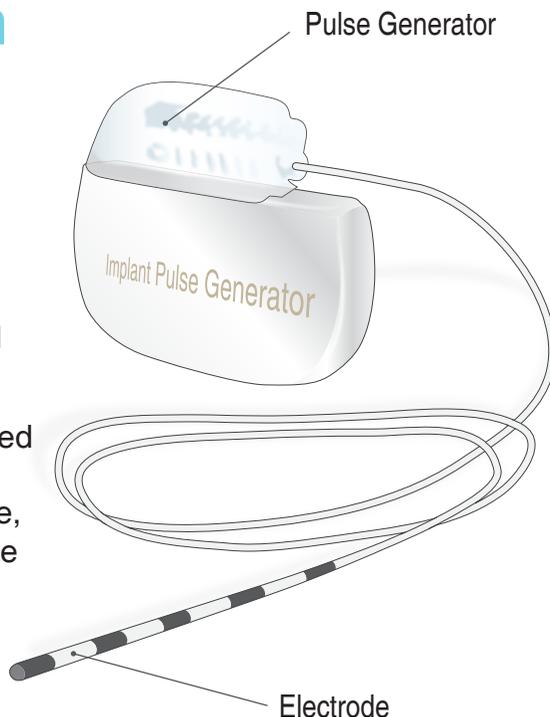
Treatment: special therapies

Deep brain stimulation

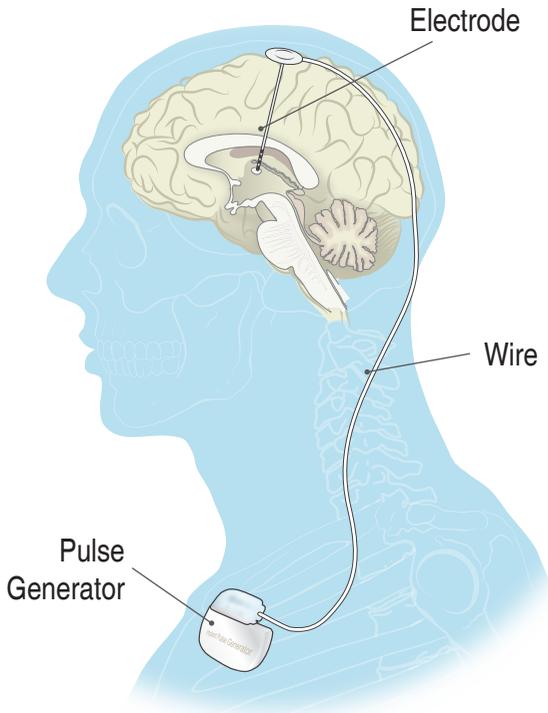
What is this?

Deep brain stimulation (DBS) is a treatment that involves surgery. Special wires (**electrodes**) are placed in one of the movement control centers of your brain. The wires are connected to a device (**pulse generator**) that is placed in your chest, just under the skin.

Once your wires are placed, you will need regular check-ups with your deep brain stimulation care team. From time to time, your team may need to adjust the device as well as your Parkinson medications. The battery for the device needs to be replaced every 5 years or so.



How does it work?



The device sends electrical currents through the wires to a specific movement control area of your brain. The electrical currents improve your motor problems by changing and controlling how movement messages are passed along in your brain and to the rest of your body.

As this treatment has similar effect as levodopa, deep brain stimulation can be thought of as ‘electronic levodopa’. However, unlike the pills, these wires are on 24 hours a day. For this reason, deep brain stimulation will not improve those symptoms that levodopa does not help (e.g. balance, speech, many non-motor problems).

Did you know?

Your brain has two sides, the left hemisphere and right hemisphere. Each side controls movement on the opposite side of your body. (In other words, the left side of the brain controls the right side of your body. In the same way, the right side of the brain controls the left side of your body.)

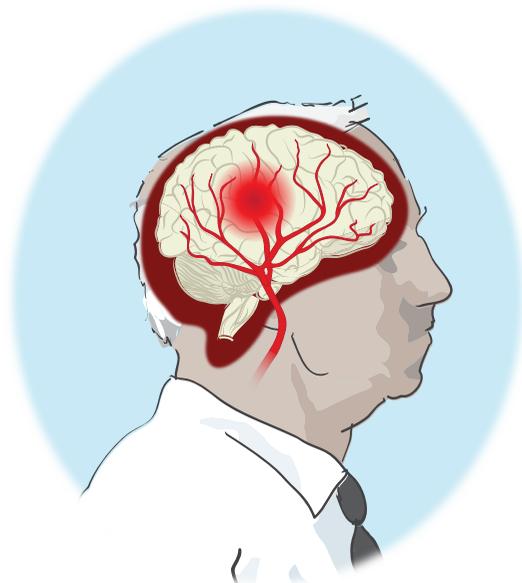
For this reason, placing wires on one side of the brain will control movement on the other side of your body. Many patients have Deep Brain Stimulation treatment on both sides of their brain eventually.

Who is this for?

Deep brain stimulation is not for everyone. This treatment is reserved for a small group of carefully-selected people with Parkinson's. You are only chosen after a very in-depth study of your current health and disease history. Many things (e.g. your response to levodopa, mood, memory loss, your current ability to reason, think and understand, and more) are reviewed in this decision.

Your doctor may consider this treatment if levodopa has worked very well for you, and:

- you have advanced Parkinson's
- you have very extreme **on and off periods** (rise and falls of when the medication does or does not work)
- you suffer from very severe **dyskinesia** (increased movements)
- the on/off periods and dyskinesia cannot be fixed with medication adjustments
- you are relatively young. (This treatment does not seem to help people who are over 70 years of age. In fact, it could make symptoms worse.)



What are the risks?

As with any type of brain surgery, there is a chance of problems (complications) after deep brain stimulation surgery. These would include:

- **brain hemorrhage** (bleeding in the brain)
- **stroke**
- **infection**

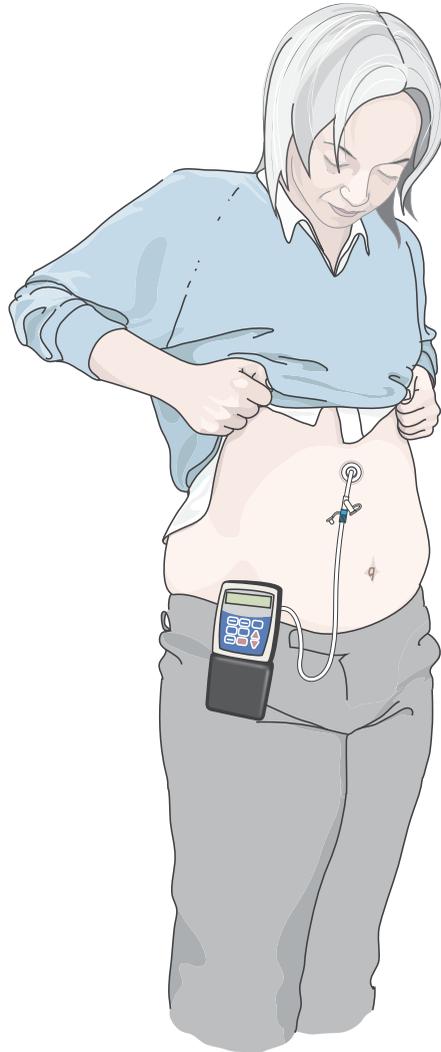
Serious, long-lasting complications are not common. However, some people can have cognitive difficulties (trouble reasoning, thinking and understanding) or speech problems. If you are offered this treatment, your surgeon will provide you more information about these problems as well as what they might mean for you.

Continuous medication

What is this?

You might think that to control **on and off periods** and dyskinesia, you just need to take a very low dose of levodopa every few minutes. Although this is a good idea in principle, it doesn't work in practice. This is mainly because the stomach does not always pass all of the levodopa to the small intestine where it can be absorbed, move into your blood, and reach your brain.

With this in mind, **continuous medication** is a treatment approach which skips the stomach altogether. **Duodopa** is a (levodopa-carbidopa) combination medication in gel-form. This medication can be delivered directly to your small intestine.



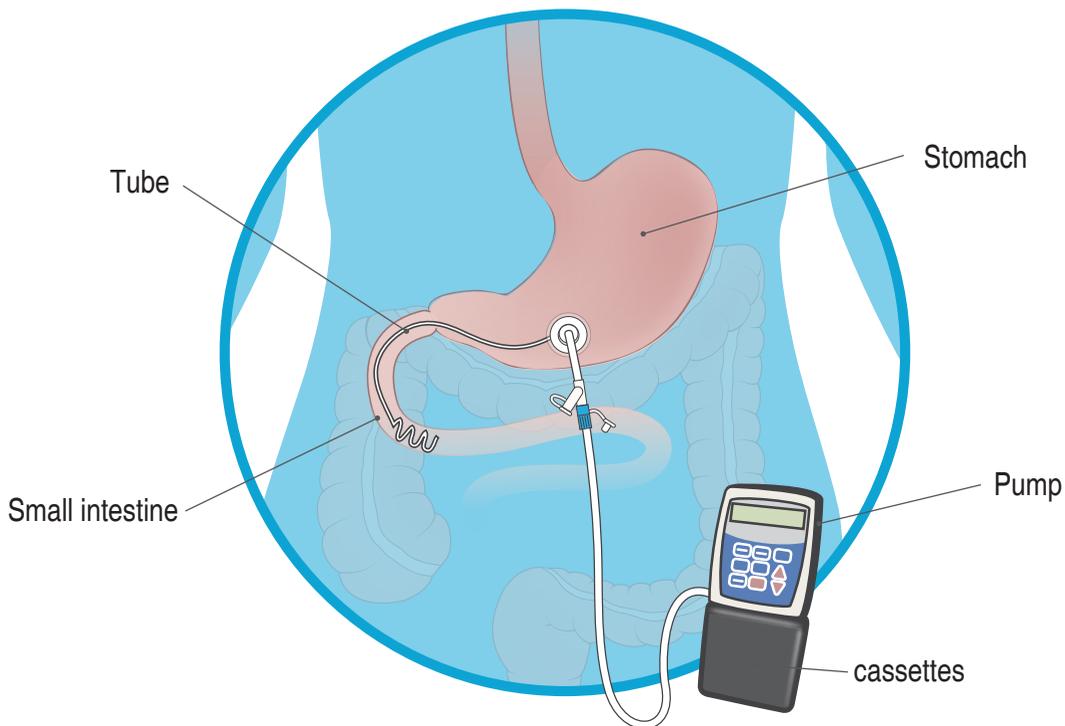
There is another method that is available in some countries (although, not typically in Canada). Continuous medication (such as, lisuride or apomorphine) is delivered through a pump that is connected to a needle under your skin. This generally has a similar effect and side effects as Duodopa. Speak to your health care team to learn more.

How does it work?

For Duodopa, a doctor inserts a small tube through the skin of your abdomen, which goes into your small intestine.

This tube is connected to a pump, which delivers low and constant doses of the Duodopa medication.

The pump can be programmed to your needs, with the option to add extra doses if you have unexpected **off times**. You wear the pump constantly throughout the day, and attach containers of medication ('cassettes') to it.



The pump is used for about 16 hours per day and cassettes are changed each day. The Duodopa system will need continuous care after it has been placed in your small intestine. It will also need to be programmed on a regular basis by a qualified professional (especially at the beginning).

In general, this treatment requires more care than **deep brain stimulation**. However, it can be reversed (that is, the surgeon can remove the tube).

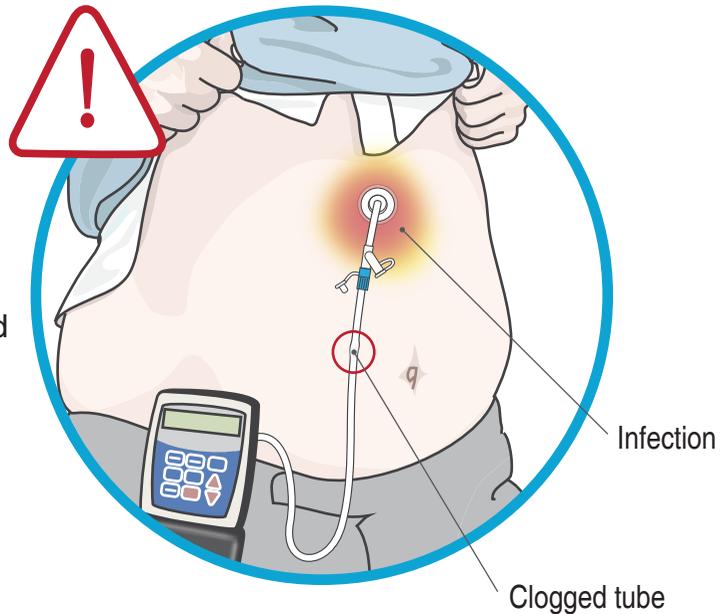
Who is this for?

Continuous medication is not for everyone. Just as with **deep brain stimulation (see page 59)**, this treatment is reserved for a small group of carefully-selected people with Parkinson's. Your doctor may consider this treatment if levodopa has worked very well for you, and:

- you have advanced Parkinson's.
- you have very extreme on and off periods (rise and falls of when the medication does or does not work).
- you suffer from very severe dyskinesia (increased movements).
- the on/off periods and dyskinesia cannot be fixed with medication adjustments.
- you do not qualify for deep brain stimulation treatment.

What are the risks?

In some cases, the skin around the tube's insertion site can become infected. The tube can also be twisted and blocked, or clogged, especially if it is not flushed frequently. Usually, you will frequently have visits with a specialized nurse to help with these issues.



What are the side effects?

The effects and side effects of continuous medication are the same as levodopa. However, you may notice your side effects are milder. Also, you may find that you have less dyskinesia (increased movements), compared to when you were taking levodopa as a pill. This is because your brain is receiving a much smoother and more constant delivery of your medication this way.

Part 3 Parkinson's Disease: Non-motor Symptoms

What are non-motor symptoms in Parkinson's disease?

Sleep Problems

- Insomnia (trouble staying asleep)
- REM-sleep disorder
- Daytime sleepiness
- Restless legs syndrome

Problems with bodily functions

- Constipation and bowel problems
- Bladder problems
- Feeling faint (sudden drop in blood pressure)
- Changes in sexuality
- Leg swelling
- Heavy sweating

Mixed (motor and non-motor) changes

- Pain
- Drooling
- Choking and trouble swallowing
- Double vision

Changes in mental ability and mental health

- Changes in mental ability
- Mood, anxiety, and apathy (feelings of no interest)
- Hallucinations and delusions
- Trouble controlling impulses

Other non-motor changes

- Changes in taste and smell
- Nausea and vomiting
- Unexplained changes in weight

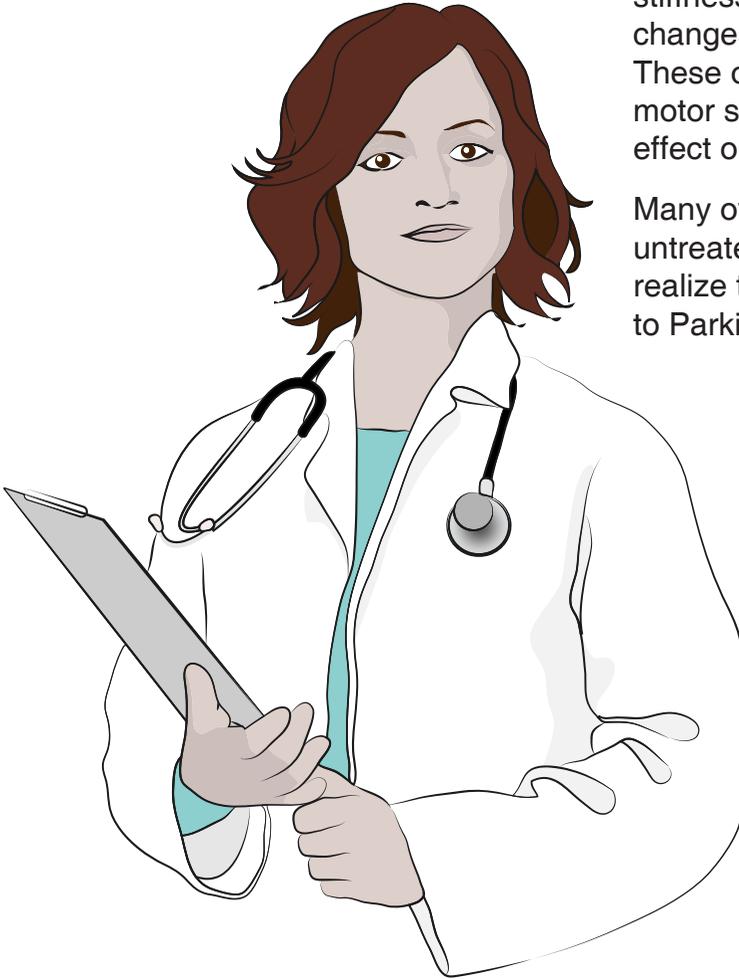
About this section

This section will help you learn about the non-motor symptoms of Parkinson's disease. It describes how to recognize them. It reviews treatments and strategies to help you manage them, watch out for serious problems, and know when to get more help.

Do not read this section from cover to cover. This may be discouraging, as there is a long list of symptoms overviewed here. Remember that many of these will never happen to you. Also, many can be controlled with treatment.

Instead, scan the table of contents on **page 4** from time-to-time, over the course of your illness. If you notice a new change and see it noted here, read that section to learn more.

What are non-motor symptoms of Parkinson's?

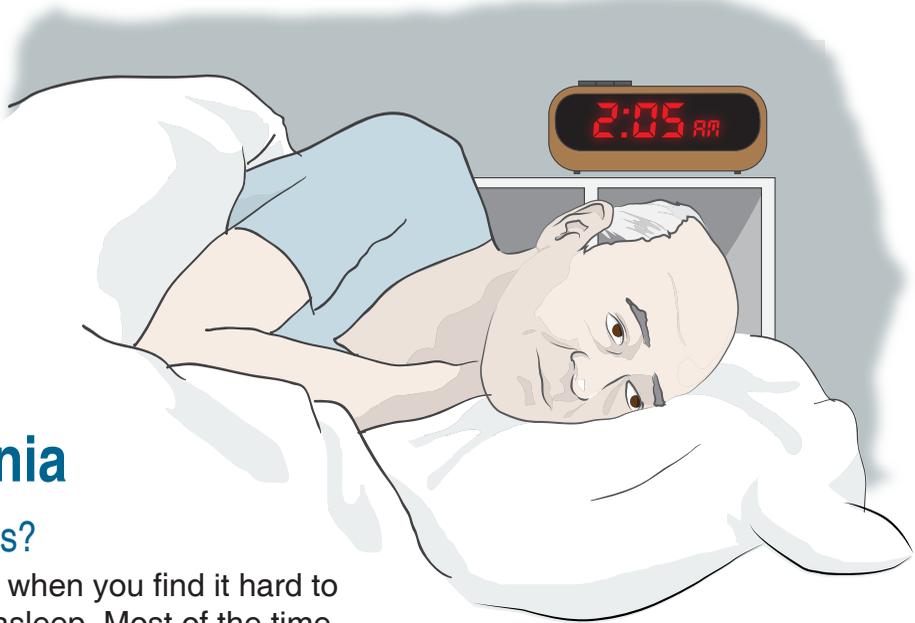


Along with tremor, slowness and stiffness, you may experience other changes with Parkinson's disease. These other changes, known as non-motor symptoms, can also have an effect on your day-to-day life.

Many of these problems go untreated, as people often do not realize that these changes are linked to Parkinson's disease.

Sleep Problems

Sleep problems are very common in Parkinson's. They are usually related to changes in the parts of your brain that control sleep. The most common problems are: trouble staying asleep (insomnia), REM-sleep behavior disorder, daytime sleepiness, and restless legs. These sleep problems are described here.



Insomnia

What is this?

Insomnia is when you find it hard to fall or stay asleep. Most of the time, people with Parkinson's have trouble staying asleep, more than falling asleep. People often find that they fall asleep quickly, but then wake up too early and are not able to sleep again.

If you do not take Parkinson's medication when you need it, this can cause insomnia as well. This is because pain, stiffness, trouble changing position in bed, or tremor can make it difficult to sleep.

Why does this happen?

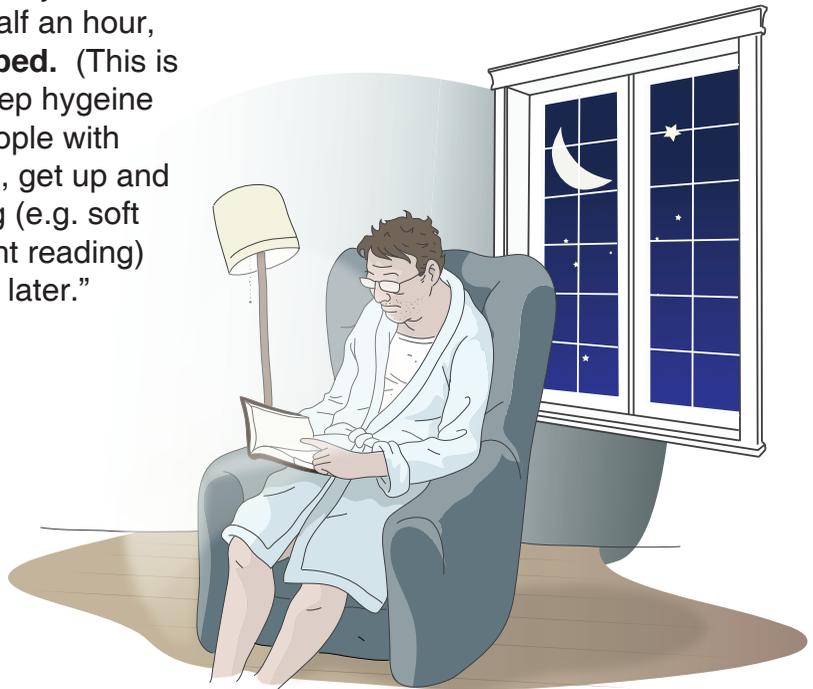
Insomnia is mainly caused by changes in the brain brought on by Parkinson's disease. However, sometimes, Parkinson's medications can also cause insomnia. For example: selegiline medication sometimes causes insomnia, especially if taken in the evening.

What can I do?

Healthy sleep habits (or sleep hygiene) can help you get better sleep. Below are some sleep hygiene tips:



- Keep regular bedtime and wake time hours as part of a daily routine.
 - Soak up bright light during daytime hours, especially in late afternoon
 - Exercise during the day.
 - Avoid caffeine after 4 p.m. (Caffeine in the morning and at lunch is fine.)
 - Use your bed for sleep and sex only.
 - Avoid naps during the late afternoon.
-
- Don't watch the clock. If you cannot sleep for more than half an hour, hour, **do not stay in bed.** (This is the most common sleep hygiene 'mistake' made by people with Parkinson's). Instead, get up and do something relaxing (e.g. soft music, meditation, light reading) and try to sleep again later."



What are my treatment options?

For many people, medications may not be the best solution. For this reason, always work on forming healthy sleep habits first. If you are still having trouble, speak to your health care team about other treatment options.

Commonly-used pills (e.g. lorazepam, diazepam, temazepam, zopiclone, eszopiclone) can help. However, sleeping pills have side effects, such as sleepiness throughout the day. Some sleeping pills can even affect your memory or your ability to concentrate.



Some recent studies suggest that medications originally used for depression (e.g. doxepin, trazodone) can help insomnia when taken at a low dose. They especially help you stay asleep. They do not seem to affect your memory. They are also less likely to be habit-forming.

Key points

- * For most people with Parkinson's, insomnia means trouble staying asleep (more than falling asleep).
- * As insomnia can be very difficult to treat, always work on forming healthy sleep habits first.
- * Medications can help, but they need to be considered with care. As sleeping pills have many side effects, they are not always the best solution.

REM–sleep disorder

What is this & why does this happen?

There are 5 stages of sleep. **REM (rapid eye movement) sleep** is one of these stages. Most dreaming takes place during REM sleep. Normally, your body is paralyzed during REM sleep. This is a good thing, as it keeps you from acting out your dreams.

With **REM-sleep behavior disorder**, this normal paralysis is lost.



For this reason, REM-sleep disorder may cause you to act out your dreams. You may shout, talk, punch, kick, or fall out of bed during this stage. You may end up injuring yourself or your bed partner. This most often happens in the early morning when people have the most REM sleep.

Many people notice REM-sleep disorder started even before having any Parkinson's movement symptoms.

What can I do?

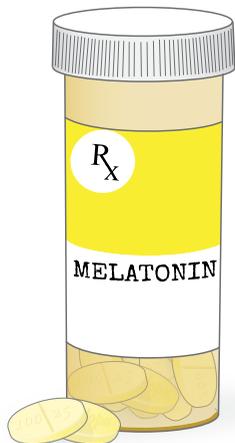
If your REM-sleep disorder is mild, you may not need any treatment.

If you become very active during sleep, you will need to think about bed safety.

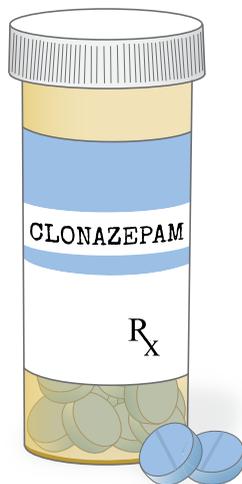
Consider using bed rails and pillows. You may even need to lay out mattresses beside your bed. If your movements become violent, you may need to sleep apart from your partner until your REM-sleep disorder is under control.

What are my treatment options?

If REM-sleep disorder becomes a problem for you, the main treatments are:



- **Melatonin**– this is the natural **hormone** that controls sleep. Melatonin is available over-the-counter at your local pharmacy. Take 3 mg at bedtime. It can be effective, and usually does not have many side effects.



- **Clonazepam** (also called Rivotril)- this can often make a big difference in REM sleep disorder. It can, however, cause daytime sleepiness and poor concentration.

Key points

- * 1 out of 3 people with Parkinson's have REM-sleep behavior disorder. It often starts even before having any Parkinson's movement problems.
- * REM-sleep disorder may cause you to act out your dreams (e.g. screaming, kicking, punching, thrashing). This can lead to injuries.
- * If REM-sleep disorder becomes a problem, speak to your doctor. The main treatments are melatonin or clonazepam.

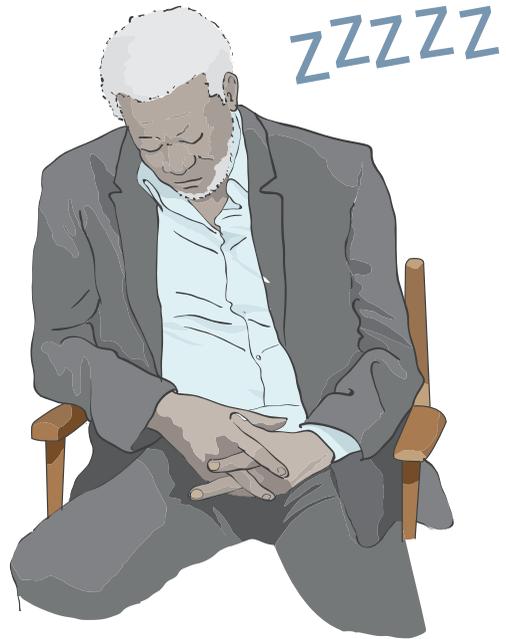
Daytime sleepiness

What is this?

Daytime sleepiness refers to feeling sleepy or sleeping too much during the day.

If you have mild sleepiness, you may fall asleep when you are inactive. If you have intense sleepiness, you may have “sleep attacks”.

During a sleep attack, you will have a sudden desire to sleep. This can happen while eating, working, walking or reading. You may even have sleep attacks while driving.



Why does this happen?

There are many reasons why you might feel sleepy. Some of these are listed below:

- Parkinson’s disease causes changes in brain areas that control sleep and alertness. If you have had Parkinson’s for a long time, this is the most likely reason that you feel sleepy.
- Sleepiness is often a side effect of Parkinson’s medications.
- Poor night-time sleep can make you sleepy during the day (However, this is usually **not** the problem, as most sleepy people with Parkinson’s actually sleep more than normal!)

What can I do?

Make sure you are getting enough light exposure during the day (walk outside if you can). You may also wish to try drinking extra coffee or tea during the day (but avoid these drinks in the evening).

Always avoid driving or operating heavy machinery if you feel even slightly sleepy.

What are my treatment options?

Your doctor might lower the strength of your Parkinson's medication. As this can bring back some movement problems, you may decide to try mild 'test' drops in your medication strength (dose). You will usually know within 1 to 2 days if this lower medication dose is helping the sleepiness or making motor symptoms worse. This can help you find your new balance point.

Your doctor may also ask you to take medication that makes you more alert (e.g. modafinil or ritalin). Common side effects of this medication are headaches, weight loss and nausea.



Key points

- * 1 out of 3 people with Parkinson's feels sleepy during the day
- * This can happen while eating, working, walking or reading.
- * Always avoid driving or operating heavy machinery if you feel even slightly sleepy.
- * Treatment options are: adjusting the dose of your Parkinson's medications, and taking medication to make you more alert.
- * Getting some sun and having more caffeine-drinks during the day can help.

Restless legs syndrome

What is this?

Restless legs syndrome (RLS) refers to the urge to move your legs in order to try to stop a difficult-to-describe, uncomfortable feeling. Moving your legs provides some comfort for a short period of time.

Typically, RLS happens when you are sitting or lying down. It tends to be worse in the evening and at night. For this reason, you may have trouble falling asleep.

RLS affects 1 to 2 out of 10 people with Parkinson's. (Interestingly, 1 out of 10 people who do not have Parkinson's also have RLS.)



Why does this happen?

The cause of restless legs syndrome is not well understood, but evidence suggests that low iron levels in the brain may be to blame, especially in areas of the brain where dopamine is used for smooth movements.

Restless legs can be associated with certain chronic conditions including kidney failure, nerve damage in the legs, pregnancy and certain medications.

RLS can be affected by the medications used for Parkinson's disease (because the treatments for RLS and Parkinson's are similar). The Parkinson's medications can change the pattern of RLS, for example moving it earlier in the day, or making it more severe.

What can I do?

If your RLS is mild, you might find that a short walk around the room, or reading for a while can help. Also, try to avoid caffeine, nicotine and alcohol at bedtime.



What are my treatment options?

Generally speaking, RLS is best treated with medication. For this reason, your doctor may discuss the following medication options for you:

- **Dopamine medications** – These medications (e.g. Levodopa, pramipexole or Mirapex, and ropinirole or Requip) also treat RLS when taken at night. However, these will need to fit with the rest of your medication schedule. Your doctor will explain what this means for you.
- **GABA medications**, e.g. gabapentin (Neurontin) and pregabalin (Lyrica). The most common side effect of these medications is sleepiness.

Iron supplements - Your doctor may suggest checking the iron levels in your blood. If your iron levels are low, taking iron supplements will help.

Key points

- * Restless leg syndrome (RLS) refers to the urge to move your legs in order to try to stop a difficult-to-describe, uncomfortable feeling. It affects 1 out of 10 people with Parkinson's.
- * Typically, RLS happens when you are sitting or lying down. It tends to be worse in the evening and at night. For this reason, you may have trouble falling asleep.
- * Treatment options include iron supplements, dopamine and GABA medication.
- * Also, try to avoid caffeine, nicotine and alcohol at bedtime.

Problems with bodily functions

Constipation and bowel problems

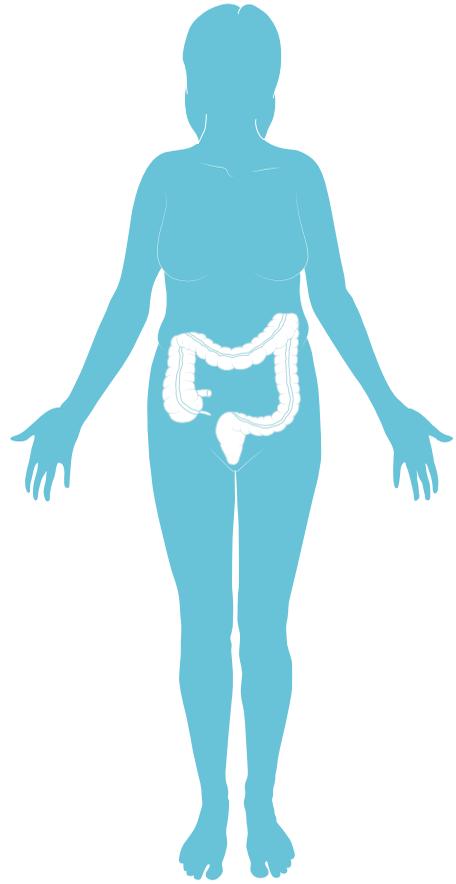
What is this?

Constipation is defined as having less than 3 bowel movements a week, or bowel movements that are very difficult to pass. This problem affects 3 out of 4 people with Parkinson's disease.

Constipation is usually easy to recognize. Bowel movements may be painful. You may need to strain. Other than the difficulty moving your bowels, you may also feel that you are not able to completely empty them. You may not feel that you can completely relax the muscles that hold in bowel movements.

On the other hand, some people with Parkinson's can lose control of stool. This is, however, not at all common, even after many years of having the disease.

Constipation is often the first symptom of Parkinson's. Some people may notice it years before having any movement problems.



Why does this happen?

Constipation is part of Parkinson's disease. It happens when the nerve cells that control bowel movements in your gut die. This slows down how food matter passes through your bowels.

Sometimes, constipation can become worse when taking medication. However, as constipation is part of the disease, medications are usually not the cause.

What can I do?

You can manage your constipation by doing the following:

1. **Drink lots of water** (at least 6 glasses a day).
2. **Eat foods that are rich in fiber**, such as:
 - bran fibre,
 - whole wheat products
 - prunes or prune juice
 - lentils and beans,
 - dried apricots
3. **Do some moderate exercise** (e.g. brisk walking, swimming, and gardening).
4. **Take bulking agents** (e.g. Metamucil) or stool softeners. These can be found at your local pharmacy and bought over-the-counter.
5. **Take Senna** - This mild laxative often helps. It is a natural herb that can be bought over the counter in pill form, or as a tea.



If you regularly have constipation, it is generally safe to take these medications every day.

Although constipation is usually not harmful, very severe constipation can block (obstruct) your bowels. This can lead to other more serious health problems. For this reason, if you have gone 1 week without a bowel movement, take the laxatives noted above and speak to your doctor.

What are my treatment options?

If the tips in the “What can I do?” section above do not help, your doctor may recommend other prescription laxatives, such as powders (Lax-a-day, Peg-a-lax) and liquid medication (Lactulose).

Key points

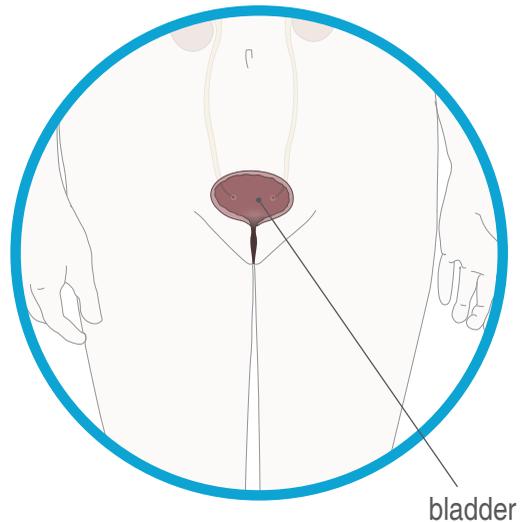
- * Constipation affects 3 out of 4 people with Parkinson's disease.
- * It is the most common first symptom of Parkinson's. You may have noticed it many years before you had any movement problems.
- * To manage constipation, drink water, eat fiber, exercise, and use bulking agents, stool softeners, or laxatives.
- * To avoid other health problems, be sure to speak to your health care team, if you have gone 1 whole week without a bowel movement.

Bladder problems

What is this?

Bladder problems affect 1 out of 3 people with Parkinson's. The most common problem is an over-active (hyperactive) bladder. An over-active bladder can cause you to:

- Rush to the bathroom (you are not able to hold it in)
- Urinate very often (that is, every 2 hours or less)
- Get up several times at night to go to the bathroom

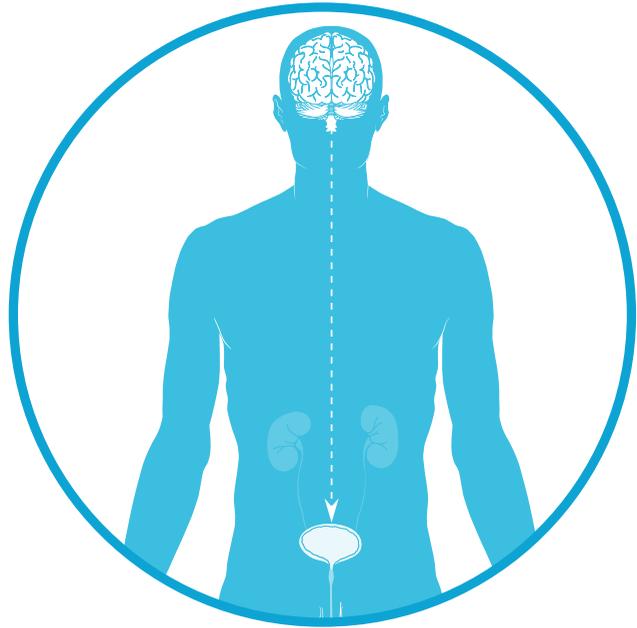


With Parkinson's, some may also experience an underactive (hypoactive) bladder. This is not as common as an overly-active bladder. If you have an underactive bladder, you can:

- Have trouble starting to urinate
- Feel that your bladder is not entirely empty (after you urinate)

Why does this happen?

The bladder muscles are controlled by the brain and those brain centres can be affected in Parkinson's disease. So, bladder problems are part of the disease process.



Did you know?

- Men who have prostate problems also need to urinate very often. These men also tend to notice that their urine stream is slow and hesitant. If the stream is not slow, the prostate is usually not the cause.
- For this reason, if you are seeing an urologist (doctor who is expert in the body's urine system), make sure they are aware that you have Parkinson's disease. If Parkinson's disease is the real cause for your bladder problem, prostate treatment (e.g. surgery) will not help.

What can I do?

You can manage your bladder by doing the following:

Follow a routine bathroom schedule

- Go to the washroom at regular times during the day. This will help, if you have overactive bladder.

Take note of the closest washroom

- This is important if you are out or in a new environment. Take note of the closest exit, especially if the washroom is not close.

Avoid large amounts of liquids and caffeine before bedtime.



What are my treatment options?

There are several medications that help with urgency (the feeling that you cannot hold it in) and the need to urinate very often. Your doctor may suggest:

- **Anti-cholinergic medications** (e.g. Oxybutynin, Tolteridone). If you are having memory problems or hallucinations, these medications can make them worse. Most of the time, this does not happen. If it does, stop taking them and speak with your doctor.
- **Dopamine medications** - Sometimes the medications you are taking for movement problems can help bladder problems.
- **Myrbetriq** - This medication helps with urgency (the feeling that you cannot hold it in).
- **Desmopressin** - This is a nose spray which can help nighttime urination, by keeping your body from making urine. Low salt (in the blood) is a rare, but dangerous side effect of this medication. For this reason, if you use this medication, you will need to take blood tests to keep an eye on how much salt is in your blood.

Key points

- * Bladder problems affect 1 out of 3 people with Parkinson's.
- * The most common problem is an over-active (hyperactive) bladder.
- * An over-active bladder can cause you to:
 - Rush to the bathroom (you are not able to hold it in.)
 - Urinate very often (that is, every 2 hours or less)
 - Get up several times at night to go to the bathroom
- * You can manage your bladder by following a regular bathroom routine and keeping note of the closest washroom when you are out.
- * There are also several medications that can help: anticholinergic medications, dopamine medications, myrbetriq or desmopressin.

Feeling faint (sudden drop in blood pressure)

What is this?

Some people may feel suddenly faint when they stand up. This faintness is caused by a drop in blood pressure. We call this orthostatic hypotension. Blood pressure drops affect 1 out of 3 people with Parkinson's.

A sudden drop in blood pressure can cause any of the following:

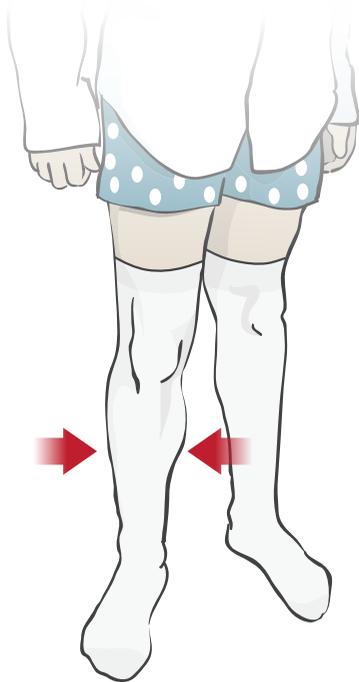
- Dizziness
- Light-headedness
- Confusion
- Headache
- Shoulder and/or neck pain



If you have a very big blood pressure drop, you can black out and fall.

Why does this happen?

Falling blood pressure is part of the disease process. This happens when nerve cells in areas of the body that control blood pressure aren't working properly. Although certain Parkinson's medications can make this problem worse, they are not the cause.



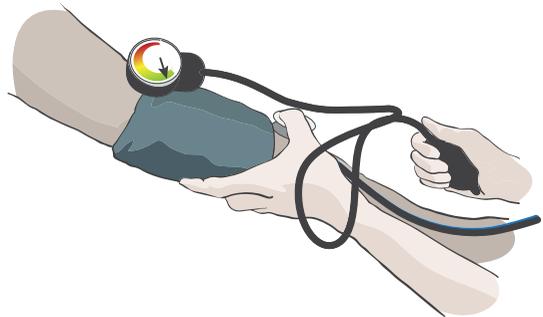
What are my treatment options?

Speak to your doctor. If you are taking high blood pressure medications or other medications that can lower your blood pressure, the first step would be to lower the strength of these medications. If necessary, your doctor will ask you to stop taking them.

What can I do?

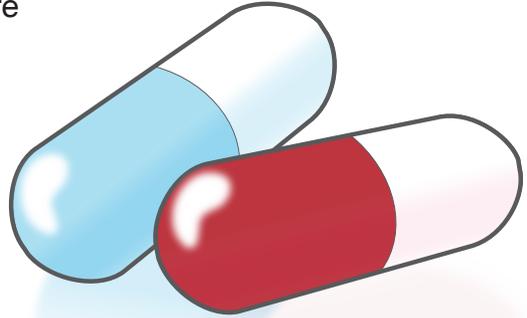
You can manage blood pressure drops by doing the following:

- Avoid standing up too quickly.
- Raise the head of your bed when you sleep. You can do this by putting a book or blocks under the legs. (It has to be the whole bed: extra pillows don't help)
- Drink plenty of water to make sure you are well hydrated.
- Watch what you eat. Be sure you are taking enough salt in your meals. Avoid heavy meals (as very large meals can lead to a blood pressure drop). Be extra careful when standing up after eating.
- Wear compression (or support) stockings. These can help by supporting healthy blood flow. These help keep blood from pooling in your legs. Compression stockings can be found in your local pharmacy.



Most people with serious blood pressure drops will need medication, such as:

- Domperidone™ (see page 48 in Part 2 – Motor Symptoms). This is usually the first choice medication. Because of heart issues the maximum dose is 3 times per day.
- Fludrocortisone™ and midodrine - A common side effect of these medications is high blood pressure when lying down.



- Pyridostigmine™ (Mestinon) - This is another option, which also can help relieve constipation. It can cause increased drooling and changes in your bladder.



- * Feeling faint is caused by a sudden drop in blood pressure. This is known as **orthostatic hypotension**. Blood pressure drops affect 1 out of 3 people with Parkinson's.
- * This usually happens when changing position, typically, when moving from standing up to sitting or lying down position.
- * You doctor may need to adjust some of the medications you are taking. Other medications (e.g. domperidone, fludrocortisone, midodrine, pyridostigmine) can also help.

Changes in sexuality

What is this?

Changes in sexuality are common. This affects 1 in 2 people with Parkinson's disease. Changes can range from a lower (or sometimes higher) sex drive, to problems with having an orgasm.

Men may find it difficult to obtain or maintain an erection. Women may have less interest in sex or have trouble reaching orgasm. It is also possible for your sex drive to go up after starting dopamine medications.



Why does this happen?

Changes in sexuality can be part of the disease process, as this is caused by dying nerve cells. That said, many other conditions can cause these changes too:

- Trouble with erection can be caused by diabetes, high blood pressure or being overweight.
- Menopause can cause a lower sex drive in women.

Keep in mind that an abnormally high sex drive can also be brought on by certain medications, which cause problems with impulse control (**see page 114** to learn more).

What can I do?

Regular exercise helps build your stamina for sexual intercourse. If you are having trouble with sexual dysfunction, consider other forms of intimacy. Speak with your partner to decide what is best for your relationship.

What are my treatment options?

Some couples are not interested in having sex. If that is the case for you, you will not need any treatment.

If sex interests you or your partner, talk to your doctor. If you are a man, your doctor may suggest medications like Sildenafil (Viagra) or tadalafil (Cialis) for erection problems.

If you are a woman, your doctor might suggest hormone medication to help with sex drive.



Keep in mind that there is a chance of having certain possible health problems when taking hormone medication. Always speak with your doctor before taking any hormones or medications for sexual problems.

Key points

- * Changes in sexuality affect 1 in 2 people with Parkinson's disease.
- * Sexual changes can include: difficulty with erections (men) or orgasm (women), as well as lower or higher sex drive (both men and women)
- * If you are a man, your doctor may suggest sildenafil or tadalafil as medications.
- * If you are a woman, your doctor may suggest hormone medication.
- * Speak with your doctor before taking any hormones or medications for sexual problems.

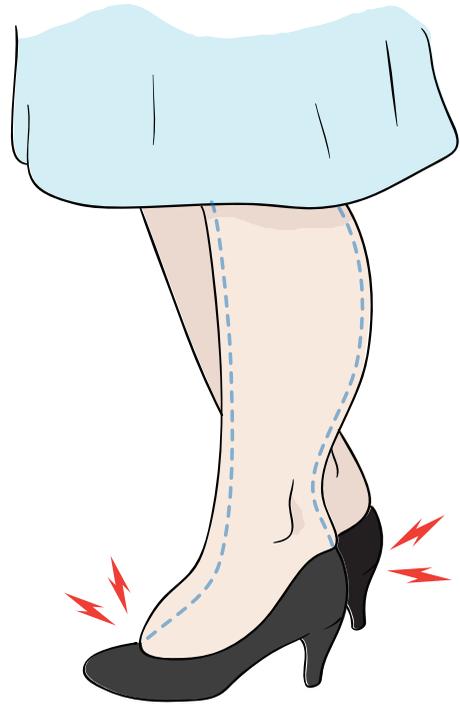
Leg swelling

What is this?

Leg swelling is a common problem for people with Parkinson's. When this happens, your lower legs become bigger. They seem to "fill with water".

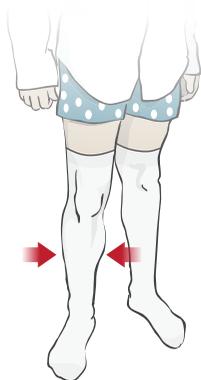
Why does this happen?

Many non-Parkinson medications (e.g. heart medications) or other health problems can cause leg swelling. So, it should not be assumed that leg swelling is related to Parkinson's. However, legs can also swell as a side effect of Parkinson's medications (e.g. dopamine medications). Amantadine medication can sometimes cause color changes in your legs, along with swelling.



What can I do?

You can manage leg swelling by doing the following:



- **Wear compression (or support) stockings.** These can help by supporting healthy blood flow. These help keep blood from pooling in your legs. These can be found in your local pharmacy.
- **Sit with your legs raised.** You can prop them up with a pillow.
- **Make sure your health care team knows about all the medications you are taking.** This will help them decide what could be the cause.

What are my treatment options?

Parkinson's leg swelling is usually not dangerous. For this reason, it is not always treated. That said, if the leg swelling is bothersome, speak to your doctor. He or she may make some medication changes.



- * Leg swelling is a common problem for people with Parkinson's.
- * Swelling can be caused by the disease itself or by Parkinson's medication.
- * Other non-Parkinson's medications or health problems can also cause leg swelling (e.g. heart disease). Be sure to tell your doctor about these. This will help him or her decide what treatment would be best for you.

Heavy sweating

What is this?

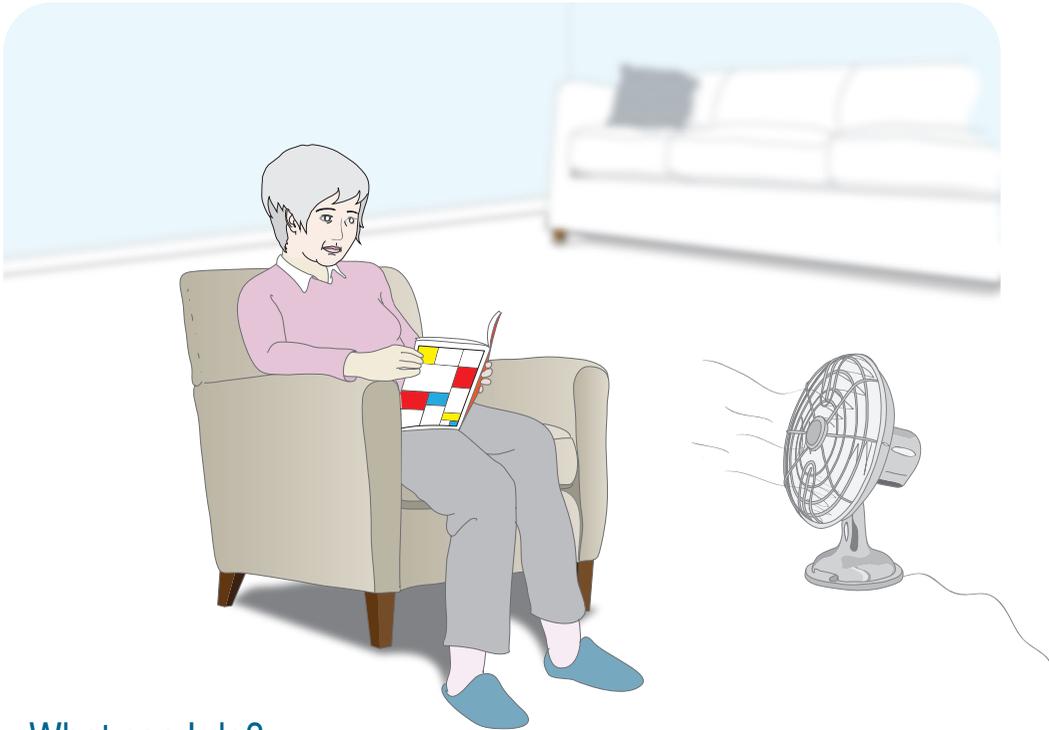
You may find yourself suddenly sweating, even with no exercise. Or, you may notice heavy sweating after only mild exercise. Heavy sweating affects 1 in 3 people with Parkinson's.



Why does this happen?

Heavy sweating usually happens during “off” periods (that is, when the medications are wearing off). It also can happen during dyskinesia (increased movements, **see page 50** to learn more), as in many ways, these extra movements are a form of exercise for your muscles.

Finally, heavy sweating can occasionally happen even without off periods or dyskinesia. We do not know the exact reason for this problem.



What can I do?

To help limit how much you sweat:

- Avoid hot or humid environments.
- Avoid heavy physical activity in the heat.
- Wear clothing that is suitable for the weather.

What are my treatment options?

There is no specific treatment for heavy sweating, as this is usually not a serious health problem. Also, medications are not often helpful. It is, however, important to watch out for when heavy sweating happens. If it happens when your medications are wearing off, it is important to share this with your doctor. He or she may change the timing of your medications, which could make all the difference.



- * Heavy sweating affects 1 in 3 people with Parkinson's.
- * This usually happens during "off" periods (that is, when the medications are wearing off),
- * It can also happen when you have dyskinesia (increased movements), as in many ways, these extra movements are a form of muscle exercise.
- * To help limit how much you sweat: avoid hot or humid environments; avoid heavy physical activity in the heat; wear clothing that is suitable for the weather.
- * If you notice this problem during "off" periods, speak to your doctor. Medications changes could make all the difference.

Mixed changes (motor & non-motor)

Pain

What is this?

Pain affects 1 in 3 people with Parkinson's. You may have other health problems (e.g. arthritis, lower back pain) that cause pain. However, if you have unexplained pain, especially in the muscles, this may be Parkinson's pain.

With Parkinson's pain, you may feel:

- Stiffness, cramps, spasms or other muscle pain.
- Different types of pain at the same time (although, usually, it feels like muscle pain.)
- More pain on one side of your body. If you noticed Parkinson's changes on one side of your body first, this is usually where it is more painful.



Why does this happen?

It is not always clear what causes Parkinson's pain.

The stiffness and unusual postures that come with Parkinson's disease may lead to muscle aches, cramps and joint pain. If the pain happens more on the side where the Parkinson's is more severe, this may be a clue that it is related to Parkinson's.

Also, another clue is if pain happens as you feel your medications are "wearing off". Parkinson's may also make you somewhat more sensitive to pain in general.

What can I do?

Stretch your muscles, have a massage, or take a warm bath. If these do not help, speak with your doctor about over-the-counter pain medications (e.g. acetaminophen or Tylenol). Do not take more than the recommended dose.



What are my treatment options?

Speak to your doctor if you have strong or intense pain. Many people have pain during “off” periods (times when the medication is not working well). If this is the case for you, ask your doctor how you might be able to cut down these “off” times.

He or she may increase the strength of your medications, or change your timing.

If pain continues to be a problem, your doctor may suggest you take other pain medications.



- * Unexplained pain affects 1 in 3 people with Parkinson's.
- * Most people have muscle aches and leg pains.
- * Your doctor may increase your medication dose.
- * Treatment options for Parkinson's pain include: over-the-counter pain medications or prescribed medications if pain does not go away. Stretching exercises, massage and warm baths can help.

Drooling

What is this?

Drooling refers to a buildup of saliva, which can lead to saliva leaking out of the mouth. If mild, saliva may pool in your mouth and very little will come out. If more serious, you may always have to wipe the sides of your mouth and chin.

Why does this happen?

You may feel as though your body is making too much saliva, but this is not the case. Instead, drooling happens because your mouth is moving less. This means that you are not naturally swallowing your saliva, so it builds up in your mouth.



What can I do?

Drooling is generally more bothersome than dangerous. However, it is possible to choke on your saliva. If this happens, speak to your health care team.

Chewing gum or sucking on a hard candy can help. This is because keeping something in your mouth gives you an unconscious reminder to swallow.

What are my treatment options?

Medications taken for Parkinson's movement problems can often lessen drooling. These medications work by improving mouth movements and swallowing.

If drooling is still a problem, your doctor may recommend atropine. One drop of this medication under the tongue can lower how much saliva you make.

- * **If you have memory problems or suffer from hallucinations, discuss this with your doctor, because you will then need to use atropine with care.**



Your doctor may also suggest you have botulinum toxin (Botox) injections. Botox is injected into the glands where saliva is made. If you use this medication, you will need injections every few months (3 to 4 months).



- * Drooling refers to saliva buildup and leaking out of the mouth.
- * It happens in 1 out of 2 people with Parkinson's disease.
- * Saliva buildup happens because your mouth is moving less. You are also swallowing less.
- * Medications can help. Speak to your doctor about atropine or botox, if drooling is a problem for you.

Choking and trouble swallowing

What is this?

Some people may notice more difficulty in swallowing. This can happen while eating or drinking, or simply swallowing saliva. If it is mild, you may not notice this at all. If more serious, you may have trouble eating. You may also choke on food.

Swallowing problems usually happen at later stages of the disease.



Why does this happen?

The action of swallowing is in fact very complex. You need a high level of muscle coordination to swallow. Many areas in the brain are responsible for it. Swallowing problems are part of the disease process. This happens when nerve cells in the areas of the brain that control swallowing don't work well.

What can I do?

Try the following to help manage trouble swallowing:

- Chew your food well before trying to swallow.
- Take small bites. Avoid large mouthfuls.
- Do not rush your meals.

To avoid choking:

- Take extra care to make sure your mouth is clear before talking.
- Eating different textures (e.g. soft or liquid) of foods may help. (Discuss this with your doctor or swallowing therapist before making any diet changes. See below to learn more)



Don't take choking lightly. Speak to your health care team right away.

If choking continues to happen, there is a chance that food can go down the wrong passage and end up in your lungs. This can lead to pneumonia (lung infection). For this reason, speak to your health care team if you notice this happening. We can help!

What are my treatment options?

Medications that treat Parkinson's movement problems can sometimes help with swallowing. Your doctor may recommend a stronger dose of your current medications. He or she may also suggest you take new medication.

Swallowing therapists (speech therapists or occupational therapists) can help. These therapists are specialized in swallowing problems. They can check how you are swallowing with special tests. They may suggest certain types of food that are easier to swallow (e.g. pureed food). They will also explain how proper posture while eating can make a big difference.

Key points



- * Trouble swallowing affects 1 out of 2 people with Parkinson's.
- * This should not be taken lightly as it can lead to choking or **pneumonia** (lung infection).
- * Treatment options include stronger doses of your regular Parkinson's medications as well as seeing a swallowing therapist who is specialized in swallowing problems.

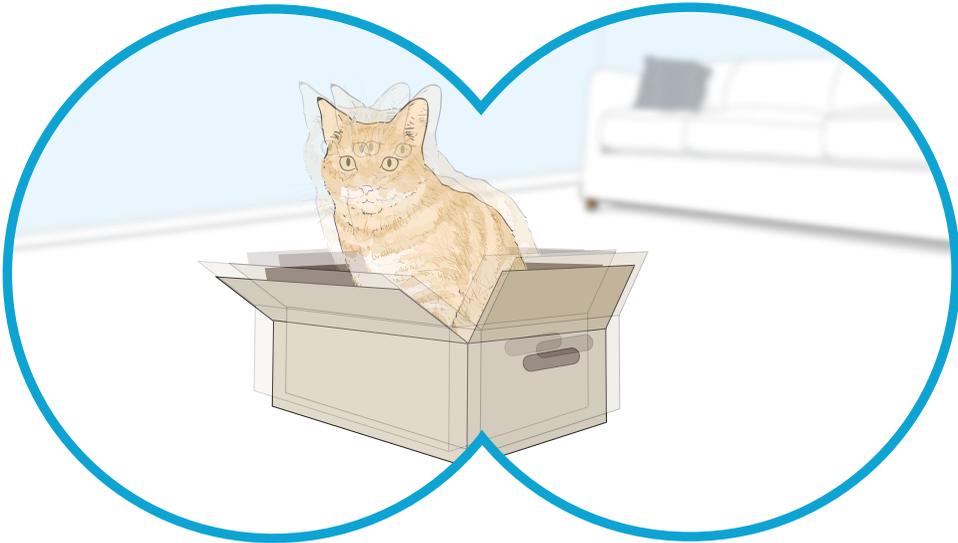


For very serious swallowing and choking problems, some people will need feeding tubes to eat properly. If this is starting to happen to you, it may be useful to begin planning ahead of time. Discuss this with your family and caregivers, if this is something that you would eventually wish.

Double vision

What is this?

Double vision is when you see two of the same thing. This is not a very common Parkinson's problem. Most often, you might have double vision while reading.



Why does this happen?

You tend to see double when your eyes drift apart. If your double vision is due to Parkinson's, this is usually caused by underactive eye muscles. (These muscles are moving less, just like the rest of the muscles in your body.)

There are many other possible causes for double vision (besides Parkinson's disease). Your doctor may refer you to an ophthalmologist (eye specialist) to confirm that there is no other cause.

What are my treatment options?

Speak to your doctor if you notice this problem. You may need to see an eye specialist. Your doctor may also strengthen the dose of your medications. Medications taken for Parkinson's movement problems (e.g levodopa, pramipexol) can help with double vision. They do this by increasing eye muscle movement.



- * Double vision is when you see two of the same thing.
- * In Parkinson's, this is usually caused by underactive eye muscles.
- * There are many other possible causes for double vision. You may need to see an eye specialist to confirm that there is no other cause.
- * Your doctor may also strengthen the dose of your Parkinson's medications as this can sometimes help.

Changes in mental ability and mental health

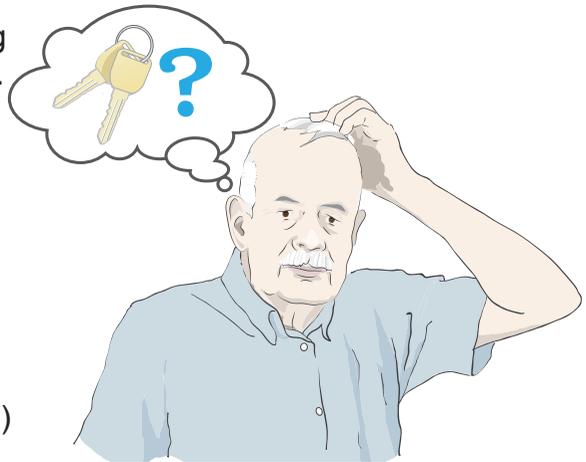
Changes in mental ability

What is this?

Some people may have some trouble with attention, thinking and memory. (This is known as mild cognitive impairment.) While somewhat bothersome, by definition mild cognitive impairment does not typically have any serious effect on your day-to-day life.

Keep in mind that forgetting some information sometimes is normal as we age. On its own, this does not mean you have dementia or any other thinking and attention problems.

Dementia refers to a much more serious failing of memory and thinking skills that affects day-to-day activities. This mostly happens in later stages of Parkinson's disease and in older people. (It is rare for anyone under 65.)



Common cognitive problems include:

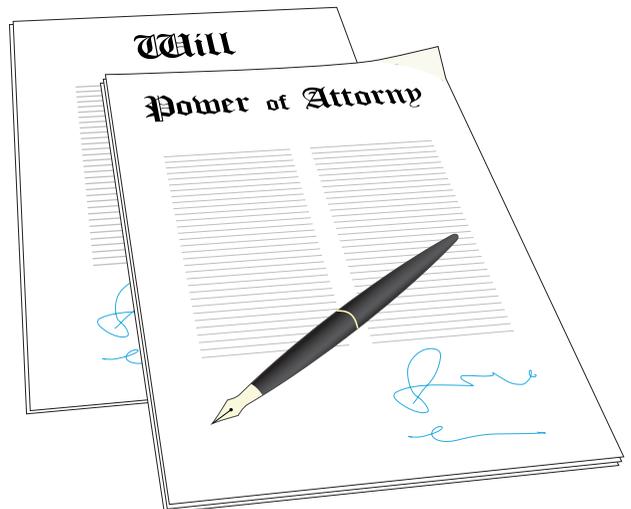
- paying attention or concentrating (e.g. trying to focus on what you are reading)
- following a complicated conversation, or solving complex problems
- planning events (e.g. organizing a busy day)
- forming thoughts quickly
- properly perceiving / interpreting things you see
- remembering events or details of events



Speak to your health care team if memory and decision-making problems start to affect your daily routines. You will need to discuss strategies, supportive care and other resources to help you manage.

If you are starting to have more serious memory problems, make sure that:

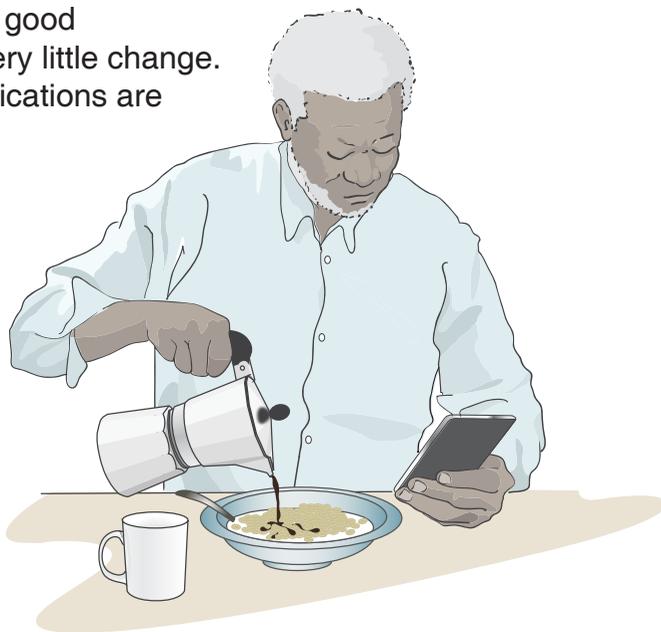
- A trusted caregiver has power of attorney. You can make these arrangements with a notary. In case you are no longer able, power of attorney will give this person the right to speak for you, arrange your finances, pay your bills and more. Without a power of attorney, the government often has to get involved. This can quickly become complicated and expensive.
- Your will is up-to-date. You will not be able to change your will if you have severe attention, thinking or memory problems.



What are my treatment options?

Medications, such as rivastigmine (Exelon), galantamine (Reminyl) and donepezil (Aricept), can help. Some people notice very good improvement while others notice very little change. Common side effects of these medications are nausea and diarrhea.

Medications used to treat sleep and anxiety problems in Parkinson's (e.g. atropine, oxybutynin, nortriptyline, sedatives) can sometimes cause attention, thinking and memory problems. They might even make them worse. For this reason, always make sure your doctor knows about all the medications you are taking.



Key points

- * Not all Parkinson's patients get cognitive troubles. Older people, and people with many years of disease have a greater risk.
- * Common changes include problems with memory, planning, attention, and slowing of thoughts.
- * Medications, such as rivastigmine (Exelon) and donepezil (Aricept) can help.
- * Be sure to tell you doctor about all the medications you are taking. Some medications can sometimes cause attention, thinking and memory problems or make them worse.
- * Forgetting some information sometimes is normal as we age. On its own, this does not mean you have dementia or any other thinking and attention problems.

Mood, Anxiety, and Apathy

What is this?

Mood and anxiety problems affect 1 out of 3 people with Parkinson's. As these problems often blend together, they will be covered together in this section.



If you are **depressed**, you may not be able to experience joy. Life may feel 'flat'. Things may not give you the same pleasure as before. You may feel tired all the time (although feeling tired can happen even with normal mood).

If you have **anxiety**, you may find yourself worrying about everyday things, even things that you should not feel anxious about (e.g. your doctor's appointments!) Some people have bursts of anxiety called "panic attacks".

Apathy is the feeling of no interest or indifference to things or life in general. You may not be interested in doing new things. You might stop hobbies that you once enjoyed, or not want to carry out your day-to-day routines. Apathy may be part of depression, but can also be a separate problem. Often, family members can feel very frustrated by this.

Depression and anxiety can sometimes begin before you have any movement problems.

Why does this happen?

Living with Parkinson's disease can certainly lead to stress and sadness. However, depression may also be caused by changes in areas of the brain that affect mood.

Panic attacks and anxiety can also happen during "off" periods (when your medications wear off). Sometimes, you may feel that you cannot breathe during these times.

This is actually your body playing a trick on you. When your medications wear off, the muscles in your chest wall can tighten. Your body may sense this as being squeezed. When this happens, you may feel short of breath. While this may be unnerving, do not worry. You are breathing just fine. This feeling will pass when your medications kick in again.



What can I do?

The support of your friends and family can make a big difference in preventing or curbing the effects of depression and anxiety. As much as you can, keep yourself active and engaged with others. Exercise, especially outdoor exercise, can help.

What are my treatment options?

In some cases, you may find it helpful to speak with a **psychologist** or another mental health professional. Certain types of psychological therapy (the commonest being “cognitive behavioural therapy”) have been shown to help depression, although they have not yet been proven to help depression in Parkinson’s.



Depression medications (e.g. nortriptyline, paxil, citalopram) that are used to treat depression in people without Parkinson’s also probably work for people with Parkinson’s.

Dopamine medications (e.g. pramipexole, ropinirole, rotigotine) which help treat movement problems can also improve depression and apathy in some people.



- * Mood problems affect 1 out of 3 people with Parkinson’s.
- * This happens when Parkinson’s disease affects areas of the brain that control mood.
- * Depression and anxiety can sometimes begin before you have any movement problems.
- * Anxiety can occur in “off” periods, and can give you the false impression that you are having trouble breathing.
- * Staying connected with friends and family, as well as exercise, can help. Your doctor may suggest depression medications or adjust your dopamine medications.
- * Speak to your health care team if you are having mood problems.

Hallucinations and delusions

What is this?

Hallucinations mean hearing or seeing things that are not really there. Hallucinations are different than feeling disoriented, having vivid dreams, or having false beliefs.

In Parkinson's, people are more likely to have visual hallucinations, that is, see something that is not there. These may start as something very minor, and non-threatening.

For example, you might notice a spot on the floor or the wall that moves or looks like an insect. If hallucinations continue to get worse, you may see animals or people.

At first, you may be aware that these hallucinations are not real. Later on, what is real and not real may become blurred. Hallucinations affect 1 out of 3 people with Parkinson's.



Delusions are false beliefs that are not based on reality or fact. Delusions may happen after you have started having hallucinations. They can be related to what you are seeing, and be a way that you 'make sense' of it.

Examples of common delusions are: believing that other people are living in your house, that a spouse is cheating or that something has been stolen. Delusions usually only happen in late stages of Parkinson's. This problem affects 1 out of 10 people with Parkinson's.

Why does this happen?

Hallucinations and delusions usually happen after years of having the disease. They may be caused in part by your medications. This may also be caused by the disease moving into the areas of your brain that are involved in making sense of what you see.

For some people who are only taking only low doses of medications, delusions and hallucinations usually happen when they are experiencing changes in their mental ability. That is, they may actually be having attention, thinking and/or memory problems (**see page 98** to learn more about this).



What can I do?

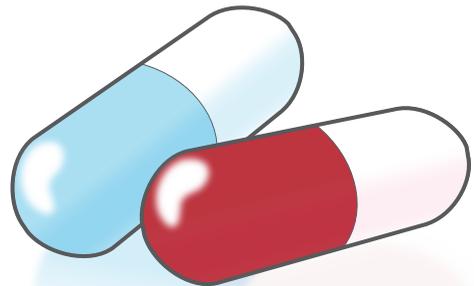
You may not need any treatment for very minor hallucinations. Either way, no matter how minor or serious these problems might be, it is important to discuss them with your health care team. We know this may be difficult. You may be afraid to talk about this. However, rest assured that there is much that can be done to help!

What are my treatment options?

If hallucinations are a problem, your doctor may try lowering the strength (dose) of some of your medications. If this makes your movement problems worse or does not help, your doctor may prescribe new medications (e.g. quetiapine or Seroquel; clozapine or Clozaril). Clozaril and Seroquel medication can sometimes make you sleepy.

Clozaril works the best. Rarely, this medication can cause a drop in certain blood cells. This can lead to other health problems (e.g. infection). To keep this from happening, your doctor will ask you to take regular blood tests so that he or she can watch this closely.

Another treatment option is to use the medications that boost your memory and cognition (see previous section). Even if your cognition is only mildly decreased, they often help a lot. They have the advantage of not making you sleepy.



- * Hallucinations affect 1 out of 3 people with Parkinson's.
- * Delusions affect 1 out of 10 people with Parkinson's.
- * In Parkinson's, people are more likely to have visual hallucinations, that is, see something that is not there.
- * No matter how minor or serious these problems might be, it is important to discuss them with your doctor. He or she may suggest lowering some of your medications, or starting new medications, (e.g. clozapine, quetiapine, cognitive medications). Speak to your health care team. There is much that can be done to help!

Trouble controlling impulses

What is this?

This problem affects 1 in 8 people who are taking certain Parkinson's medications called *dopamine agonists*. (see page 52) Trouble controlling impulses is also called impulsive, uncontrolled behaviour (ICDs).

These can include:

- Excessive gambling
- Hyper-sexuality – This refers to feeling preoccupied with sexual feelings and thoughts and/or having much more interest in sexual arousal. This can lead to sexual behavior that is 'out of character', or that might be harmful to yourself or others.
- Binge eating
- Compulsive shopping
- Carrying out pointless tasks over and over again. (This is known as *punding*.) Examples of this are: repeatedly taking apart a device and putting it back together, or sorting and resorting different items).



Why does this happen?

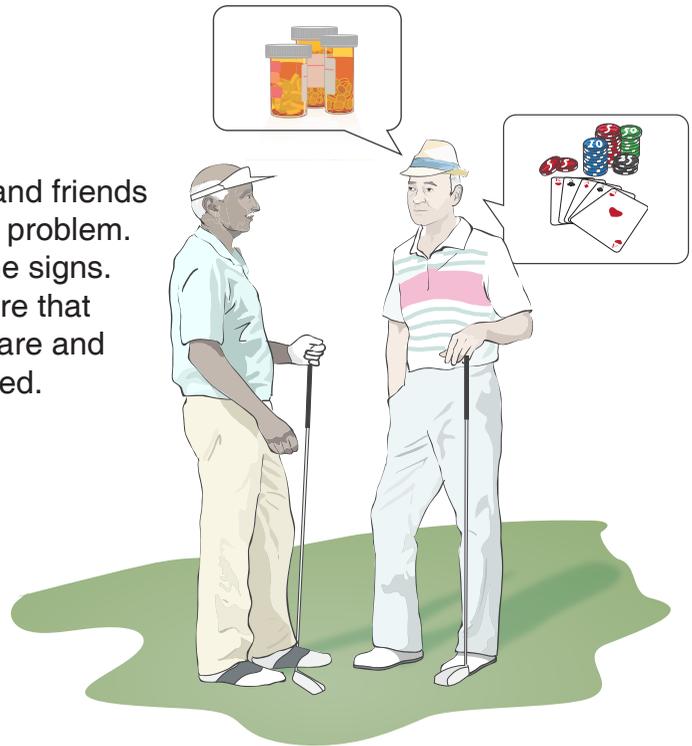
This problem is usually a side effect (or unwanted reaction) of your medications. Certain dopamine medications (Pramipexole (Mirapex), ropinirole (Requip) and rotigotine patch) are most likely to cause you to have trouble controlling your impulses.

What are my treatment options?

Since this is usually a medication side effect, your doctor will usually lower the strength (dose) or your medications. This will usually solve the problem. Sometimes, though, when medications are stopped or adjusted, your movement problems can become worse. If this happens, your doctor may suggest other medication changes.

What can I do?

Make sure that your family and friends are aware that this could be problem. Ask them to watch out for the signs. This way, they can make sure that your health care team is aware and you can get the help you need.



Key points

- * This problem affects 1 in 8 people who are taking certain types of Parkinson's medications.
- * Often, this can lead to changes in your behavior (e.g. excessive gambling, hyper-sexuality, binge eating, and compulsive shopping).
- * To treat this problem, your doctor will usually lower the strength (dose) or your medications. If needed, he or she may suggest other medication changes.

Other non-motor changes

Changes in taste and smell

What is this?

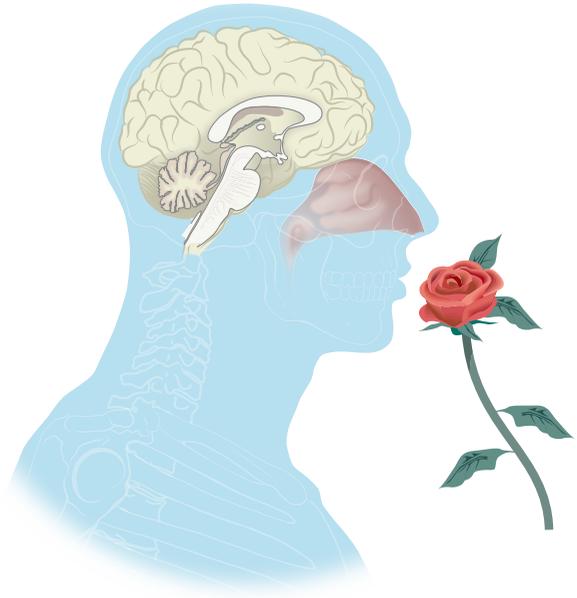
Almost all people with Parkinson's will have changes in the ability to smell, and 1 out of 3 people will have no sense of smell at all. You may also notice changes in taste, as your sense of smell is directly linked to taste.

People do not often notice these changes right away as they come on slowly over time. You may notice in general that you have difficulty making sense of smells. You may also have trouble telling two smells apart. Some people notice that their food tastes bland. Some cannot smell the strong odors that others around them can.

Generally, this is not a dangerous problem.

Why does this happen?

Loss of smell is part of Parkinson's. This is caused by dying cells in areas of your brain that control your sense of smell. Changes in smell often happen years before you notice any movement problems.



What can I do?

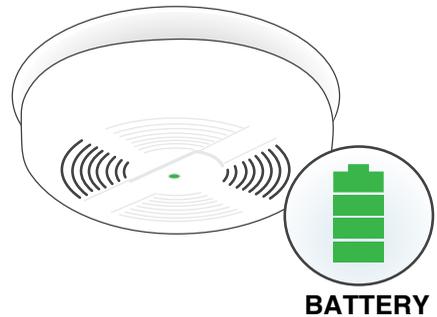
You might notice a loss in appetite. It is important to continue eating a full and balanced diet all the same.



Also, since you may not be able to smell some dangerous odors, be sure that your smoke detectors are installed and are always in good working order.

What are my treatment options?

There is no treatment for changes in taste or smell.



Key points

- * Almost all people with Parkinson's have changes in taste and smell
- * This problem is not dangerous.
- * Currently, there is no treatment available for this problem.

Nausea and vomiting

What is this?

Nausea refers to an uneasy stomach and the feeling that you might throw up. You may also have a stomach ache and/or feel bloated.

Why does this happen?

Nausea usually begins when starting a new medication. It typically goes away on its own with time (even if you stay on the medication). Sometimes nausea can be caused by slow stomach emptying, which is caused by disease affecting nerve cells in the stomach.



What can I do?

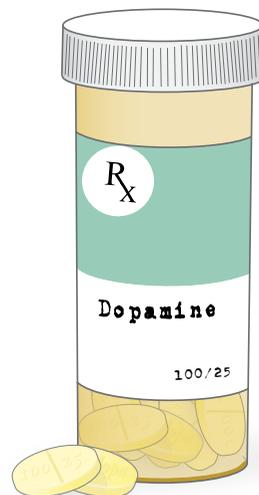
Taking your medications with meals (or with a small snack) may help with relieve nausea. However, this can slightly reduce the absorption of certain medications, such as levodopa.

If your nausea is very bothersome, it can cause you to stop eating. If this happens to you, speak with your doctor.

Please note that that certain nausea medications used by people without Parkinson's (e.g. Stemetil or Maxeran) can make your movement problems worse. For this reason, always speak to your doctor before trying a new medication. Stemetil or Maxeran should be avoided.

What are my treatment options?

If your Parkinson's medications are causing your nausea, your doctor may prescribe domperidone (Motilium) medication. Domperidone blocks the effects of dopamine in your stomach and intestines, without blocking its benefit in your brain. Your doctor might also suggest you take reflux medication.



Key points



- * Nausea usually begins when starting a new medication.
- * Usually, it will go away on its own with time (even if you stay on the medication).
- * Treatment options include: domperidone medication, and sometimes, reflux medication.

Unexplained changes in weight

What is this?

Many people with Parkinson's notice changes in their weight. In general, weight loss is more common than weight gain. It is common for people with advanced disease to lose weight despite eating more.



Why does this happen?

We still do not understand the exact reasons for Parkinson's weight changes. It could be related to nausea which is caused by your medications. It can also be caused by dyskinesia (increased movements). That said, weight changes can be seen even if you do not have dyskinesia or nausea.

You will not usually have a greater appetite with Parkinson's. If you do feel the urge to binge eat (and gain weight as a result), this may happen after starting certain medications (e.g. pramipexole (Mirapex), ropinirole (Requip) and the rotigotine patch). This is because these medications are likely to cause you to have trouble controlling your impulses (**see page 108** of this guide to learn more.)

What can I do?

Try the following to manage any weight loss:

- Try taking your meals during “on” times (when the medication is working well). You will find it easier to use utensils and you may also have less difficulty swallowing.
- Try high-calorie foods (even sweets are allowed!)
- Drink liquid diet supplements (Boost, Ensure)
- **See page 112** of this guide, if you have nausea and/or vomiting.



What are my treatment options?

There is no medication that treats weight changes in Parkinson’s. However, there are other strategies that can help. Speak to your health care team if you have concerns about how you are eating.

Key points

- * Many people with Parkinson’s notice changes in their weight.
- * Treatment options include: treating the cause (e.g. nausea), eating high-calorie foods and during “on” times (when the medication is working well).

Part 4

Frequently-asked Questions

You will likely have many questions about your Parkinson's. While we cannot know what all of these might be, we can certainly try to cover some of the most common topics that people discuss with us in our clinics.

Making sense of your Parkinson's

What stage of disease am I in?
Are there different types of Parkinson's?
What does 'tremor predominant' and 'akinetic-rigid' mean?

Looking forward and planning for the future

What is my prognosis?
Can my doctor predict how people will do?
What can I do to prepare for my future?
What is my families' risk for Parkinson's?

Medications & treatments

Can I take generic pills?
How about vitamins? Herbal supplements? Other 'Alternative' therapies?
What should I expect from treatment with dopamine medications?
What is "wearing-off" ? What does this feel like?
Do I have to take my medication at the same times every day?
What do I do if I'm late taking my pill?
I don't feel any "off-times". Does that mean the medications aren't working?
Do the medications stop working? Should I save them for when I'm really bad?
I am interested. How can I take part?

Should I avoid levodopa to prevent dyskinesia or fluctuations?
Is levodopa toxic to my dopamine neurons?
Can dopamine treatments slow the progression?
What about stem cells?
Does that mean there will be no new treatments to slow the progression?

Work & getting around

Should I tell my employer that I have Parkinson's?
Can I drive?
Do I have to inform my local motor vehicle licensing authority?
Can I travel?
How about jet lag and time changes?

Parkinson's research

Why is Parkinson's research so important?
Why might someone take part?
Are there any advantages or disadvantages to taking part in research?
What should I clarify or check before joining any study?

Making sense of your Parkinson's

What stage of disease am I in?

There is no one way to define your stage of disease. 'Stage' of disease is meant to explain everything about your disease right now, using a number. The simplest staging system (that is also used most often) is called **Hoehn and Yahr staging**. The stages range from 1 to 5. They are mainly based on whether your symptoms are on one or both sides of your body, and how your balance and walking are. However, your Parkinson's as a whole is too complex

to be summed up this way. For this reason, staging is often quite difficult to do.

While your 'Hoehn and Yahr' stage might be interesting to know, it does not provide any real information about the rest of your disease. This means staging is not really very useful for your care and treatments.

For these reasons, we do not use just one staging system at our clinic. Instead, we use many rating scales for the different signs and symptoms we see.



Are there different types of Parkinson's? What does the 'tremor predominant' and 'akinetic-rigid' mean?

Everybody with Parkinson's is different. Different people can have very different symptoms and speed of progression. Recognizing this, neurologists have tried to divide patients into different subtypes (or groups, or categories) of Parkinson's.

'Tremor-predominant' and 'akinetic rigid' is one of the early ways that doctors divided patients into groups.

- 1. Tremor-predominant Parkinson's:** As the name suggests, people most often experience tremor with this type of Parkinson's. Tremor-predominant Parkinson's may advance more a bit slowly than other types.
- 2. Akinetic-rigid Parkinson's:** People with this form of Parkinson's tend to see more slowness, stiffness and trouble walking.

This is just one of many ways of dividing Parkinson's into different subtypes. While it may be interesting to label your Parkinson's this way, knowing your Parkinson's type will

not really help predict what care you will need. The best approach is to deal specifically with you and your individual issues as they arise.

Looking forward and planning for the future

What is my prognosis?

Your health outlook for the future is called your **prognosis**. Knowing your prognosis is one of the most important questions, but also one of the most difficult to answer. The main reason is that no two people are alike. For some, Parkinson's may advance quite quickly. Others may continue for many years before they have any serious challenges or problems.

Most people do very well once treatment has started. They are able to go back to doing all the activities of their normal day-to-day life. We

sometimes call this the 'honeymoon' period. Your 'honeymoon' can continue for many years to come. For others, it may only last a few years.

The honeymoon period ends either when you begin to have trouble with motor fluctuations (e.g. "off-times", see **page 48** or non-motor problems. That said, even after this honeymoon period is over, you still may be able to manage quite well with medication changes. Speak to your health care team regularly about your Parkinson's and any problems you have noted. They will explain what this means for you.

Can my doctor predict how people will do?

Not perfectly. As a general rule, Parkinson's in younger people tend to have more "on-off periods" and dyskinesia (see below). However, their Parkinson's also tends to advance more slowly. Their medications tend to offer them better control of their symptoms. They also

have less **non-motor problems**.

People with balance problems early on in the disease tend to have a worse **prognosis**. For some people, a combination of non-motor problems, (e.g. early changes in mental ability, REM-sleep disorder, and episodes of feeling faint after a sudden drop in blood pressure) may predict a worse outcome. To learn more, **see Part 3**.



What can I do to prepare for my future?

It is always important to plan ahead. If you are doing very well and at early stages of the disease, there is less to plan. That said, you may want to redo your financial planning, especially if you are still working. Your planned retirement age may shift. You may wish to take your big vacations soon, while you are able to do everything.

If things are more advanced and you are not doing so well, keep in mind, that planning and making changes takes time. For this reason, there are a few other things you will need to consider ahead of time. Try to plan for what your health needs might be 1 to 2 years from now:

- Will your current home be the best place for you? (e.g. Do you

have to climb stairs constantly?)

- If you have it, does your insurance plan need to be revised (for critical illness, disability coverage)?
- How do you get around most often (long car commutes, public transport)? Might this need to change?
- Do you have dependents (children, parents) in your care? Will you need help to care for them over time?
- Do you need to assign a power of attorney? (see **page 100**)
- Will you need more help to manage? (Social workers, occupational therapists, and clinic nurses are extremely important here.)

Finally, all people (including those without Parkinson's) should spend a bit of time with their family outlining what they would want if their health suddenly worsened and they could no longer speak for themselves.

Questions to consider:

- How aggressively would you want to be treated?
- Would you want feeding tubes if you couldn't eat for yourself?
- Would you want CPR?
- Would you want to have a breathing tube if you can't breathe on your own?

It may be painful to talk about this, but it is important. While you will not be able to foresee all the possible future scenarios, make sure your loved ones have a good general idea of what your wishes might be. Especially if you are alone, write things down in a living will.



What is my families' risk for Parkinson's?

Please see the section "Who gets Parkinson's disease" on **page 16**.

Medications & Treatments

Can I take generic pills?

Most Parkinson's medications now come in generic form. In general, there is no advantage in taking name-

brand medications over the generic types. For this reason, very few patients take name-brand versions. Save the extra money for something worthwhile.



How about vitamins? Herbal supplements? Other 'Alternative' therapies?

We find it quite distressing to watch people get taken in by sham alternative or complementary therapies that have not been proven to work.

Sometimes the therapies are relatively harmless, but sometimes there are serious side effects. Our other concern is the cost. The general rule of thumb is: the more expensive the 'alternative' therapy is, the more likely it is to be fraudulent. Do keep in mind that once an 'alternative' therapy has been shown to work, it is generally no longer considered 'alternative'. It will become part of standard Parkinson's care.

If you are interested in alternative or complementary therapies, below are a few options you might consider.

These have had a good amount of research to show that they are safe and have benefits for Parkinson's patients:

Multivitamins: In general, keeping a balanced diet has much more of a health benefit than taking lots of vitamin supplements. That said, levodopa can cause a rise of a chemical in your body (called homocysteine). This might increase your chances for vascular disease (illnesses that affect your blood vessels). This effect on homocysteine can be blocked if you take B vitamins. They are found in:

- Green leafy vegetables
- Bread (in North America, B vitamin is added.)

A simple over-the-counter multivitamin - use these if you don't get many B vitamins in your diet. (again, no need to take a big dose.)

Vitamin D: Vitamin D is important for strong and healthy bones. You can get plenty of Vitamin D from the sun, from spring to fall. However, if you spend lots of time indoors, especially during winter, over-the-counter Vitamin D pills (1000 IU per day) are safe.

Senna, or Senokot: The herb, Senna, treats constipation in Parkinson's very well. It comes in tea or pill form.

Tai chi and Dance: Tai chi (a Chinese movement technique) has been proven to prevent falls in Parkinson's. Some studies have found that dance may also have similar benefits. If you are at risk of falling, you may want to look into tai chi or Parkinson's dance groups. These classes (usually found online) are available in most cities. Speak to your local Parkinson's society representative if you have questions or trouble finding them.

There are currently no other herbal supplements, homeopathic medications or alternative treatments that help Parkinson's.

Some plants (e.g. mucuna pruriens) contain small amounts of **levodopa**. Unfortunately, the amount is so small and varies from plant to plant. So taking this will not offer you a high enough or steady dose to control your symptoms properly. These plants also do not have **carbidopa** (see **page 42 to learn more**) which is added to dopamine medication to prevent side effects and increase benefit.

Research on acupuncture and chiropractic care has also found no proven benefits for Parkinson's patients. There is simply no evidence to show that these therapies work.

That said, do not lose hope. Parkinson's disease is a very active area of research. More options will become available in time!

What should I expect from treatment with dopamine medications?

In general, it depends on the type of treatment you have. If you are taking levodopa, you should notice clear improvement in your movement and muscle control (e.g. less stiffness, faster walking, clearer voice, and more). Levodopa will also help to improve tremor (although not always at lower doses).

Overall, you should more or less feel yourself again. If you do not, then your treatment (or diagnosis) may need to be changed.

The other dopamine medications also help, but the difference may not be as dramatic.

To learn more, see the **treatments** and **medication** chapters in **Part 2** of this guide.

Do I have to take my medication at the same times every day?

At early stages of Parkinson's, wearing-off or "off-times" (see **page 48**) is not an issue. For this reason, you do not have to take your medication on an exact schedule. You can take your medication at slightly different times every day for more flexibility. You can continue to do this, as long as your medication is keeping steady control of your symptoms (that is, you do not notice wearing off).

If you do start to notice "off-times", you should take your medications on a fixed schedule. This will help prevent any wearing-off, so you can have better control of your symptoms throughout the day. (Usually, by this time, you will be able to feel something different if you are late.)

What do I do if I'm late taking my pill?

The best thing is to take your dose as soon as you remember. You will then need to adjust the schedule for the pills you need to take over the rest of the day. There is no one set rule for this, and it depends on how the medications affect you. For example, let's say you need to take your medication every 3 hours (9AM, noon, then 3PM...). If you miss your 9AM and only remember at noon, you might:

1. Take your 9AM pill right away (at noon). Then, take your noon-time dose 1.5 hours later (that is, 1:30PM). Finally, take your 3PM, 6PM, and so on, as scheduled.

OR, you could also take another approach:

2. If you are still feeling well, take your 9AM pill right away (at noon). Then, skip your noon-time pill, just this time, but take your 3PM, 6PM, and so on, as scheduled.

Usually it is best to take pills on an empty stomach, before you eat. If you've forgotten and now have a full stomach, that's ok. It is more important that you take the pills right away. You will just need to keep in mind that its effect may not be as strong this time.

If you are late or miss doses regularly, you may need an electronic reminder system. Most pharmacies will sell these. Another option to consider is a smart phone application, which can set up reminders for you.

I don't feel any "off-times". Does that mean the medications aren't working?

Not necessarily. In early Parkinson's (and especially with older people), medications don't wear off in the same way. Your body tends to be able to 'store' medication to have a more long-lasting effect. Sometimes,

your medication effects might even last for a few days or weeks.

For this reason, you might not notice any difference if you have not taken your medications for less than a day. That said, if you stopped taking your medications for a longer time, you would slowly notice your symptoms coming back and getting worse with time.



Do the medications stop working? Should I save them for when I'm really bad?

No, **do not** stop taking your medications because you are worried about future changes. There is no such thing as 'saving your medications for later'.

Dopamine medication works very well for people with Parkinson's. However, as the disease advances over time and more of your dopamine neurons age, you will need a stronger dose of this medication. You may also need to take your medications more often (or start taking other long-acting medications alongside it). This is because the medication's effect will not last as long, over time.

Finally, you might begin to notice more non-motor symptoms over time (e.g. trouble sleeping, problems with bodily functions, and changes in mental ability). These changes cannot be treated with dopamine medication. These changes are not happening because of the medications you are taking. Instead, it is the disease that is changing over time.

Studies have shown no benefits to delaying your treatment. Treatment is there to help you to carry out your daily activities, so you can lead a fulfilled and productive life. This will not be possible if we stop or delay treatment.

Should I avoid levodopa to prevent dyskinesia or fluctuations?

It is true that on average if you delay levodopa (that is, start other medications first), you get dyskinesia and fluctuations later (**see page 44-49** to learn more). However, since these medications are less effective, you would also have less control of your symptoms. Keep in mind that dyskinesia is a sign that your treatment is working well, (just a bit 'too well' in this moment).

In general, you need not worry about dyskinesia right away:

- If you are 70 or over when your Parkinson's started, it is not likely that dyskinesia will ever be a big problem.

- If you are very young (less than 50), dyskinesia will eventually become an issue. However, at that point, there will be other treatments you can consider with your doctor to control this. For young people, we sometimes start with other medications (**see page 54-57** to learn more), especially if your symptoms are relatively mild.

Research has shown that all people need levodopa and that delaying this medication for more than 1 or 2 years will not help you in the long-run. If anything, it only makes your quality of life (your overall level of health, comfort and well-being) slightly worse. In other words, putting up with disability for years to save a few weeks of dyskinesia is simply not worth it.



Is levodopa toxic to my dopamine neurons?

No. When levodopa was first developed, people wondered if it could damage the nerve cells. However, over time, it has become clear that this is not true. Even for people who were wrongly diagnosed with Parkinson's (and took very high

doses of dopamine medications for over 30 years), no nerve cell damage was found.

It can sometimes feel as though these medications are making you worse. This is because, over time, you need more and the disease is continuing to advance. However, this has to do with the disease changing, not your medications doing damage.



Keep in mind: Parkinson's will continue to advance, even if you do not take levodopa.

Can dopamine treatments slow the progression?

Just as dopamine treatment does not speed up the disease, it probably does not slow it down either.

It is only in situations where people received very poor treatment (and because of this, were not able to exercise and stay active), that we see lack of treatment causing permanent disability.



What about stem cells?

Stem cells (also known as the 'cells of youth') are cells that are not yet specialized. They are able to grow and divide, and have the potential to become any type of cell in your body, (including a nerve cell).

Researchers are fascinated by stem cells as they are a wonderful research tool. We are even now able to make stem cells grow from adult tissue. These cells are being used to study how disease works, test new treatments, and more.

That said, we are a very long way off from putting stem cells inside of you to replace missing cells. We cannot simply place stem cells into your brain. This is because stem cells have to:

- Survive your immune system (the part of your body that fights infections and outside elements to keep you alive and healthy).
- Grow new connections to become part of your current brain network (and without causing a cancer to grow!).

These are just a few of the major challenges that scientists are still trying to better understand.

Also, Parkinson's disease affects many areas of the brain. So, placing stem cells into only one area may not help much.

Much of stem cell Parkinson's research over the last 25 years has

been focused on how dopamine neurons might be replaced. However, this did not make patients better and had some serious side effects. So, unless there is a major, unexpected research breakthrough, it is not likely that you will have implanted dopamine stem cells as part of your care. Still, there may be other, unexpected ways that stem cells will be useful in the future.



Does that mean there will be no new treatments to slow the progression?

No! The future of Parkinson's care is very bright. There are many active areas of research with lots of promise.

Researchers are:

- testing ways to reduce synuclein (a chemical in your brain that is linked with Parkinson's) levels in your brain
- stop synuclein from sticking together to damage neurons
- prevent synuclein from spreading from cell to cell

- protect the energy burning centers of your cells (called mitochondria),
- reduce inflammation in the brain, and much more!

Some of these treatments might eventually dramatically change the way that Parkinson's disease progresses over time. These treatments are already being tested with Parkinson's patients. So, although we cannot know what will happen, this is still a very exciting time in Parkinson's research. There are plenty of reasons to have hope.

Work & getting around

Should I tell my employer that I have Parkinson's?

It is really up to you to decide when you want let others know about your diagnosis. Your decision to tell others at work will depend on:

- Your relationship with co-workers and employers
- How you might expect they will respond to your news

Many employers are accommodating and will take steps to keep you working as long as you wish. However, in harsher or highly-competitive work environments, employers and coworkers may use your diagnosis as an 'excuse' to pass you over for promotions or give you less interesting tasks.

If you are in a job that demands consistently high performance, you may need to ask others to help watch how you work. Sometimes you may

not be performing as well as you think. Ask a trusted colleague for their feedback and advice. This can be a big help.

Finally, keep in mind that in some professions you **must** inform your employer (**mandatory disclosure**). This is especially critical in fields where you or others could be in danger if you are not doing your job well (e.g. health care workers, airline pilots, professional drivers, etc.).

Remember, being diagnosed with Parkinson's does not mean that your career or work life is over. If your medication is giving you good control of your symptoms, your job performance may not be affected. Your Parkinson's may not even be noticed by your employer and colleagues for years.

Can I drive?

It depends. There are many reasons to be cautious about driving, such as:

- slow reaction time or reactive movements
- problems with perception (i.e. how you see, hear, feel and interpret the world around you)
- sleepiness (including sudden sleep attacks while behind the wheel)
- trouble seeing, and more

Usually, you should be able to drive safely if you have all of the following:

- Mild motor changes (that is, you are still able to do intense exercise)
- Good balance and can walk without any aids (Trouble walking can be a sign that your feet move too slowly)

- No trouble seeing (especially, at night)
- Good distance judgment
- No trouble with memory and concentration
- No sleepiness

If any one of these is not true, do not wait. Talk to your health care team. Also, if you are still driving, ask a friend or family member to sit in the passenger seat and watch you. If they are worried, that is an important sign. If you are not sure and would like an objective opinion, see an occupational therapist and take an on-road test.

Remember, Parkinson's sometimes impairs your ability to stay awake, even causing sudden sleep attacks. If you get sleepy while driving, pull over and rest. Even if you normally drive well, never drive when you are feeling 'off' or even a bit sleepy.

Do I have to inform my local motor vehicle licensing authority?

Yes. Most government authorities require that you report any changes in your health situation. In most areas, your doctor must also file a report to the motor vehicle bureau, stating that you have Parkinson's. Once you or your doctor have filed this report, they may also ask for yearly updates. If you do not provide this information, there can be serious consequences, especially if you have an accident.

How about jet lag and time changes?

It is not always easy to figure out how to take medications when there are time changes. As a rule of thumb, take your medications at their usual 'wake' frequency. For example, if you take levodopa every 4 hours while awake, keep taking it during that extra long day, every 4 hours.

To manage jet lag when travelling east (when you have to go to bed earlier than your body wants) you can also take 3mg of Melatonin, at the time you wish to sleep. (This is safe for Parkinson's)

Can I travel?

You can usually travel without restrictions, as long as you do not have advanced Parkinson's. That said, make sure you have travel insurance, and make sure you share all your health information to your insurance company. (Some companies will look for an excuse not to pay you only after something has happened.)

Parkinson's research

Why is Parkinson's research so important?

We would never be able to advance Parkinson's disease treatment without research. It is the key to finding a cure and improving care. Many of the treatments that you will be receiving are available because countless patients in the past took part in research.

Why might someone take part in research?

For many people with Parkinson's, taking part in research is a chance to 'pay it forward' to others who will follow. It is a chance to be part of the future of Parkinson's care. That said, taking part in research is a personal choice. You should never feel pressured or forced.

Are there any advantages or disadvantages to taking part in research?

The purpose of research is to better understand treatment and Parkinson's in general. For this reason, you may not see any direct or instant benefit from taking part in a research study. In any research study, there is a chance for benefit. However, there is also a chance for no benefit or for harm. (If we were already certain that the new drug would benefit you, it wouldn't be research!)

What should I clarify or check before joining any study?

Before taking part in any study, there are few things to understand and check:

1. Did you sign a consent form?
A consent form is meant to explain the study to you in clear language. It will include a clear discussion of all the potential risks and benefits. This consent form must be approved by a research ethics board (look for a stamp of approval). You should not join any study if you have not read, understood and signed this form.
2. Is the research study being carried out by a reputable organization?
This might be, for example, an accredited university or hospital, (one that is known to meet high quality standards for research, teaching and learning). If you are unsure, ask the doctor who is treating your Parkinson's.
3. Do you understand the commitment you are making when you agree to take part? Do you know what they expect you to do? Joining a study could mean more clinic visits, filling out forms or questionnaires, or doing more tests. You should also check how this might affect your current Parkinson's treatment and whether your caregivers will need to help. If you think that you will probably not be able to manage all the study's commitments, it is better not to participate at all.
4. Finally, did they ask you to pay?
You should never have to pay to take part in a research study. If you are asked to pay, the 'study' is probably fraudulent.



Keep in mind that all the standard medical treatments are available to you, whether or not you take part in research. You do not have to be in a study to receive the best treatment or care.

What questions should I ask before I agree to take part in a study?

- Who is doing this study?
- Who approved it?
- What question(s) is this study trying to answer?
- Will I receive payment for taking part?
- How long will the study last?
- Who will know that I am taking part?
- Who do I contact if I have any questions or concerns?
- What are the benefits to taking part in this study?
- Are there any risks (or possible harm)?
- Will this study better help me to understand my Parkinson's?
- Will I miss out on any "normal care" if I take part?

Before making any decisions, ask as many questions as you need. Below is a list of important questions. (Keep in mind that not every question may apply to every study.)

- Could my Parkinson's get worse during the study?
- Is it possible that I receive only a placebo (dummy pill that has no effect)?
- If I decide to take part, how will this affect my day-to-day?
- Will I need to take tests or have procedures?
- What will happen to any samples (e.g. blood) I give?
- Are there any other options available to me, if I decide not to take part?
- What will happen to me at the end of the study?
- Will you send me the results of the study?
- After I agree to participate, can I change my mind? How would I remove myself from the study?



You have the right to understand what the research is about and what it will mean for you to take part.

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**Office d'éducation des patients
Patient Education Office**



 Parkinson Canada