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A **Guide** to the *Non-Motor Symptoms* of **Parkinson's Disease**



A patient-friendly booklet for:

This booklet is to help you understand Parkinson's Disease and prepare for the treatments ahead. Please review it with your family. Bring it with you to your clinic appointments.



Centre universitaire de santé McGill
McGill University Health Centre

**This booklet was prepared by
Ron Postuma & Christos Galatas**

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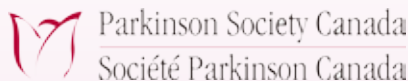
IMPORTANT! PLEASE READ

This booklet is intended as a general guide to non-motor symptoms of Parkinson's disease. It is important to realize that everybody is different. Therefore, you may never experience many of these symptoms, and some of the treatments that we discuss may not be ideal for you. We list some of the common side effects of treatments, but there are always potential side effects that we do not mention. Speak to your treatment team, who can help plan the best treatment for you.

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

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INTRODUCTION



What is Parkinson's Disease?

Parkinson's disease (PD) is an illness which is caused by a slow breaking down (or degeneration) of nerve cells in the brain. Degeneration is a process similar to aging. As we age, cells in our body begin to work less efficiently. Some eventually die. When you have Parkinson's disease, some areas of your brain are 'getting older' faster than the rest of your body.

What are the Motor Problems of PD?

A person with Parkinson's disease gradually loses the ability to have complete control of their body movements. You may experience these as changes that appear slowly over time. They are also called motor symptoms and can appear in a variety of ways. The most important of these are:

- **slowness of movement** – Movements of the hands, legs, voice, and face are slowed, and there is less spontaneous movement.
- **shaking (or tremor)** – This often occurs in the hands, legs, or jaw, usually when the limb is resting (that is, not while you are not using your arms or your legs.)
- **stiffness (or rigidity)** – Your doctor will detect this during your check-up.
- **walking problems** – This includes slow walking, getting 'stuck' or frozen in place, and loss of balance.

Parkinson's disease is a condition that is **chronic**. This means that it will continue over a long period of time. It is also progressive, which means that it may worsen over time. The good news is that we now know a fair amount about the disease. Also, many of its symptoms are treatable. We currently have a number of treatment options available to patients that can ease the problems of the disease.

What is this booklet for?

While the treatment of the motor problems of Parkinson's disease is important and complex, it is not the focus of this booklet. This booklet is focused on the non-motor parts of PD.

Other than tremor, slowness and stiffness, you may experience other changes with Parkinson's disease. These other changes, known as non-motor symptoms, can also impact your quality of life. Many patients may also not realize that these other symptoms are linked to Parkinson's disease. As a result, they go untreated.

This booklet will help you learn about these symptoms and discuss how you can recognize them. It will provide information on treatments and strategies to help you manage these symptoms, any serious problems to watch out for, as well as when and how to get more help.



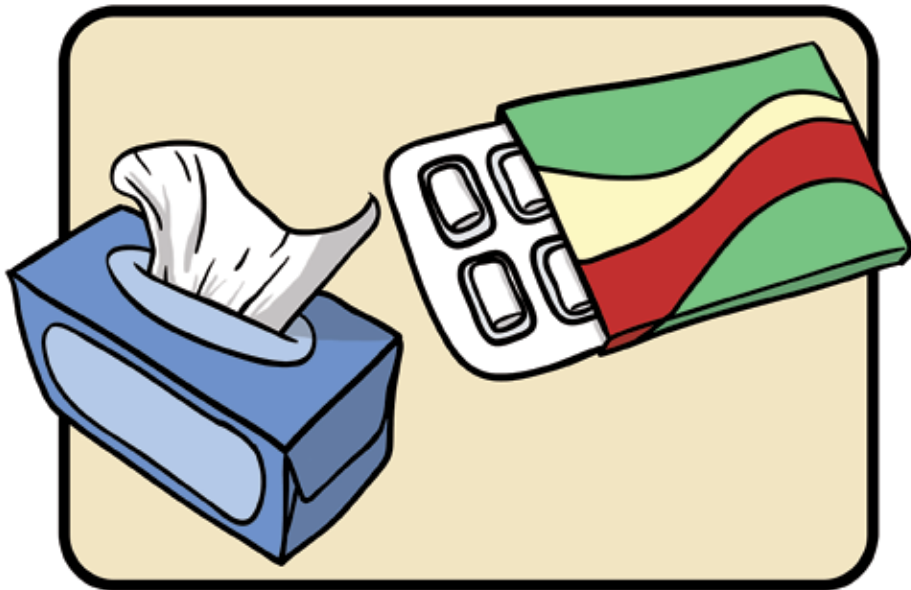
The NMS-Quest

You will find a **non-motor symptom questionnaire** called the *NMS-Quest*, at the end of this guide. This questionnaire is meant to help individuals with Parkinson's disease to identify any non-motor problems that they might have. You may wish to tear out this questionnaire, and complete it as you read through this booklet. You may then discuss your answers as well as any questions or concerns that you have with your doctor at your next visit.

Refer to the last page of this booklet for a copy of the *NMS-Quest* questionnaire.



Drooling



What is this?

Drooling occurs when there is a pooling of saliva, that results in saliva leaking out of the mouth. If mild, saliva may pool in your mouth; however, very little will come out. If severe, you may always have to wipe the sides of your mouth and chin.

Why does this happen?

Drooling occurs in half of people with Parkinson's disease. Drooling feels like your body is making too much saliva, but this is not the case. It is, in fact, caused by decreased mouth movements and swallowing. This results in a build up of saliva in your mouth.

What can I do?

Chewing gum or sucking on a hard candy can help. Having something in the mouth gives an unconscious reminder to swallow, and so drooling lessens.

Although drooling is generally an irritation rather than a dangerous symptom, occasionally you might choke on your saliva. If this occurs, speak to your doctor.

What are other possible treatments?

Medications taken for motor symptoms of PD often prevent or decrease drooling. These work by improving mouth movements and swallowing.

If drooling is still a problem, your doctor may recommend atropine. A single drop under the tongue decreases the production of saliva. People with memory problems or hallucinations need to use atropine carefully. Sometimes, this drug worsens these symptoms.

Your doctor may also suggest injections of Botulinum toxin (Botox). This is injected into the glands that produce saliva. Botulinum toxin reduces the amount of saliva that is formed. If you use Botulinum toxin, you will need injections every few months.

KEY POINTS

- Up to one half of people with PD drool
- Saliva pools in the mouth and leaks out
- Caused by decreased mouth movements and swallowing
- Treatment options: Atropine or Botulinum toxin

Change in Taste & Smell



What is this?

Smell is altered in almost all people with PD. One third of people with PD will have no sense of smell at all. Taste can also be affected, since smell is directly linked to taste.

Changes in taste and smell are often unnoticed because the changes are gradual. You may notice a decreased overall ability to smell. You may have difficulty telling two smells apart. Some people notice that their food tastes bland, or they always find themselves adding more salt or spice. Some cannot smell strong odours that others around them can.

Why does this happen?

Loss of smell sensation is part of the process of Parkinson's – the degeneration affects areas that are responsible for detecting odours. Changes in smell can occur years before changes in movement.

What can I do?

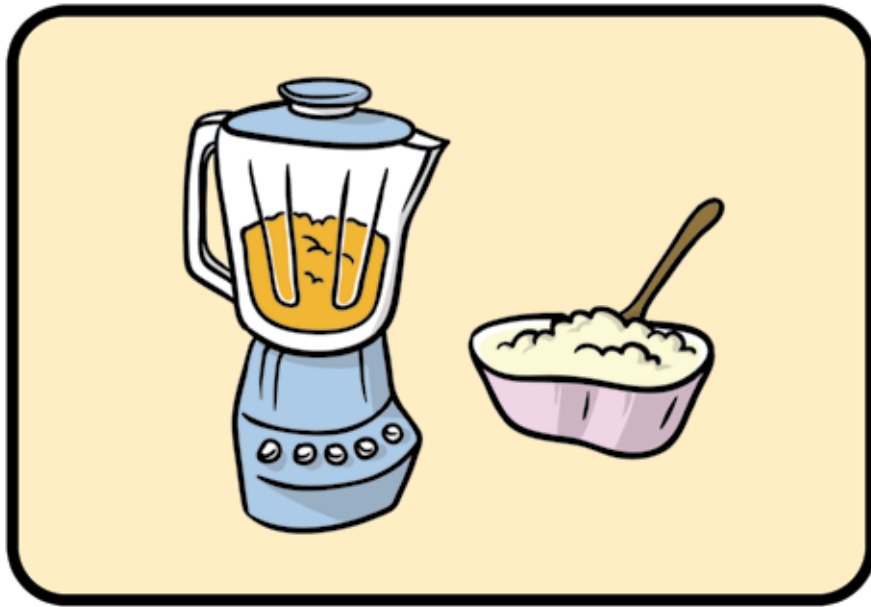
What are other possible treatments?

There is no treatment for changes in taste and smell. Generally, this is not a dangerous symptom. It can result in some loss of appetite – it is important to continue eating a full balanced diet. Because you may not be able to smell some dangerous odors, ensure that smoke detectors are installed and are in good working order.

KEY POINTS

- **Almost all people with PD have changes in taste and smell**
- **Currently, there is no treatment available for this symptom**

Choking & Swallowing Difficulties



What is this?

Occasionally, patients notice more difficulty in swallowing, generally with food or drink, but also with swallowing saliva. Swallowing problems usually occur in more advanced disease. In mild cases, you may be unaware of swallowing problems. In severe cases, you may have trouble eating. You also may often choke on food.

Why does this happen?

Swallowing is a very complex motor activity that requires a high degree of muscle co-ordination, with a wide range of areas in the brain responsible for it. Therefore, it is not hard to imagine why swallowing troubles happen. In general, swallowing troubles are part of more advanced PD.

What can I do?

It is important to not rush your meals. If you choke while eating and talking, you may need to ensure your mouth is clear before talking. If you are having consistent choking, it is very important to talk to your doctor. Food can go down the wrong passage, and can end up in the lungs. This may result in pneumonia (lung infection).

What are other possible treatments?

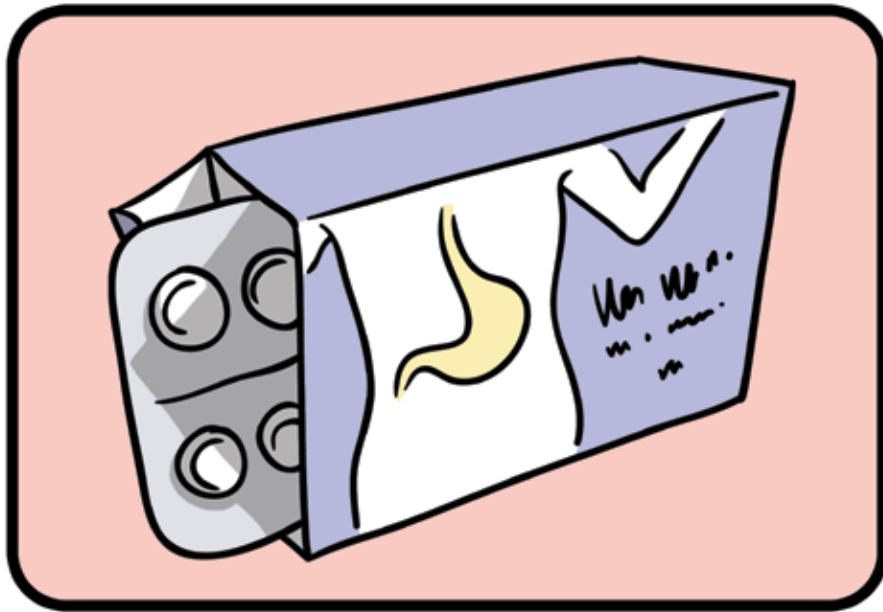
Treatments that improve motor symptoms of PD can sometimes improve swallowing. Your doctor may recommend increasing your current dose or may offer a new Parkinson treatment.

Swallowing therapists (speech therapists or occupational therapists) can also help. These therapists are specialized in assessment of swallowing problems. They typically assess swallowing with special tests. Certain types of food that are easier to swallow may be recommended. Proper posture while eating will also be taught.

KEY POINTS

- **One half of people with PD have trouble swallowing**
- **Trouble swallowing can result in choking or pneumonia**
- **Treatment options: Increasing regular PD treatments; Swallowing therapists**

Nausea & Vomiting



What is this?

Nausea is a sense of unease in the stomach, with a feeling of possible vomiting. Sensations of stomach ache and bloating also can often occur with Parkinson's.

Why does this happen?

The most common cause of nausea is starting a new Parkinson's drug. All Parkinson's medications can cause nausea and vomiting, but some tend to cause this more than others. A feeling of stomach bloating can also be present in Parkinson's, usually related to slow stomach movements. In this case, it may not be related to treatment.

What can I do?

If nausea and vomiting appear with a new drug, these symptoms often go away by themselves, even if you stay on the medication. Taking your medications with meals (or with a small snack) may help with these symptoms. However, this can slightly reduce the absorption of certain medications, such as levodopa.

If nausea is very bothersome, it can cause you to stop eating – if so, you must speak with your doctor. You should also be aware that certain medications often used for nausea in people without Parkinson's (ex. dopamine blockers, such as Stemetil) can make motor symptoms worse and should be avoided.

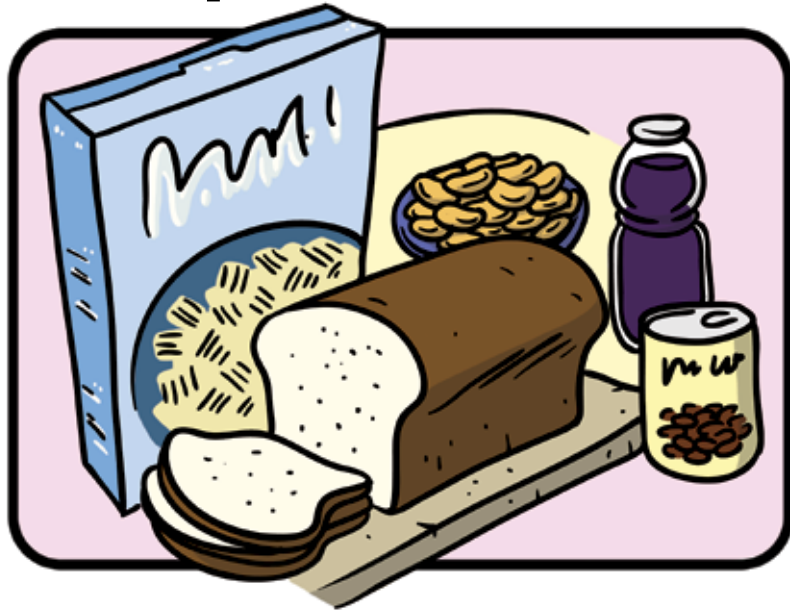
What are other possible treatments?

If Parkinson's treatment causes nausea, your doctor may prescribe domperidone (Motilium). Domperidone blocks the effects of dopamine medications in the stomach, without interfering with their benefits in the brain.

KEY POINTS

- Nausea often begins when starting a new Parkinson's drug
- This symptom may not persist when related to a new drug
- Treatment option: Domperidone may help if symptoms do not improve by themselves

Constipation



What is this?

Constipation is defined as having less than three bowel movements a week, or excessive straining to pass stool. It affects three out of four people with PD. Generally, constipation is an easy symptom to recognize. Other than the difficulty moving your bowels, you may also feel that you are unable to completely empty your bowels or that you are unable to completely relax the muscles that prevent bowel movements.

Why does this happen?

Although constipation can occasionally be increased by medications, people usually have this symptom regardless of drug treatment. Constipation is related to degeneration of the nerves in the bowel that control bowel movements. That is, it is part of the disease itself, not caused by Parkinson treatment. Constipation can be the first symptom of Parkinson's. You may have noticed it years before you had motor problems.

What can I do?

Constipation can be treated. Make sure you drink enough water. Also add fibre to your meals. Foods rich in fibre include:

- bran fibre
- whole wheat products
- lentils and beans
- prunes or prune juice
- dried apricots

Moderate exercise can help. You can also purchase bulking agents (Metamucil) or stool softeners over the counter. However, many people need laxatives or enemas to relieve constipation. Over the counter laxatives (Senokot) can help. This treatment is available in pill form or as a tea.

Although constipation is usually not harmful, very severe constipation can cause obstruction of the bowels, with medical complications – if you have gone a week without a bowel movement, take the laxatives above and talk to your doctor.

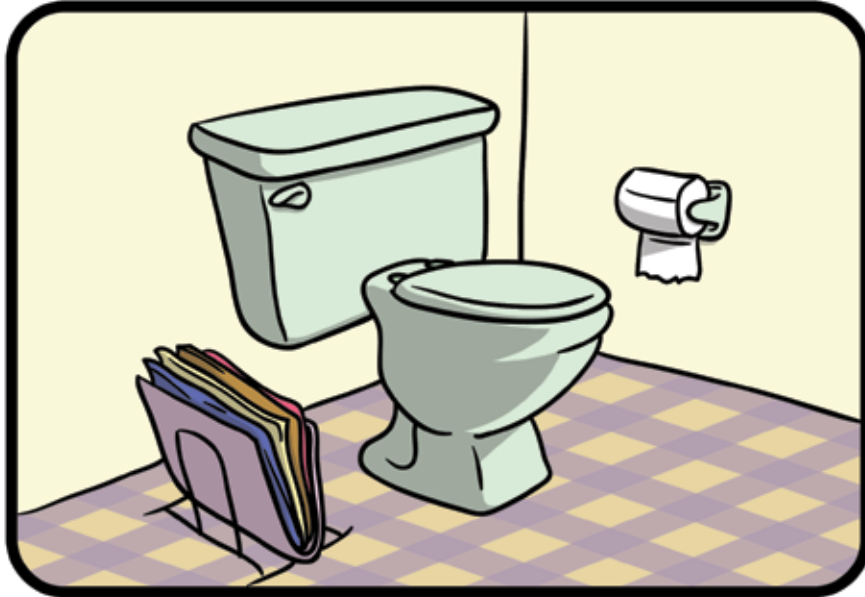
What are other possible treatments?

If the above treatments don't help, your doctor may recommend additional prescription laxatives.

KEY POINTS

- **Three in four people with PD suffer from constipation**
- **This can be an early sign of Parkinson's disease**
- **Treatment options: Drink water, eat fibre, exercise and use bulking agents, stool softeners, or laxatives**

Uncontrolled Loss of Stool



What is this & Why does this happen?

Loss of stool is not necessarily due to diarrhea (which is not very common in PD). It refers more to an inability to control bowel movements, with incontinence, or 'accidents'. This is a quite rare feature of PD, and is not ever experienced by most patients. In mild cases, you may be unable to control when you pass gas, or you may have only a small amount of leakage. Total loss of control occurs in the most severe cases. This is rare. People with uncontrolled loss of stool usually have uncontrolled loss of urine.

What can I do?

If the incontinence is caused by inability to move fast to the bathroom on time, try to develop a plan to get you there on time. It may be useful to schedule a bathroom trip before times that you often have accidents. You can find a range of incontinence products at health supply stores.

What are other possible treatments?

Medications used to treat PD may improve uncontrolled loss of stool, both by improving control and helping you get to the bathroom on time.

KEY POINTS

- Rare
- PD medications can improve uncontrolled loss of stool

Bladder Dysfunction

What is this?

One third of people experience a bladder-related problem with PD. The most common problem is an overly active (hyperactive) bladder. A hyperactive bladder can cause you to:

- rush to the bathroom (or you would be unable to hold it in)
- urinate frequently (less than every two hours)
- get up multiple times at night to go to the bathroom

With PD, you may also experience an underactive (hypoactive) bladder. This condition is much LESS common than a hyperactive bladder. Symptoms include:

- difficulty starting urination
- a sensation of not completely emptying your bladder
- leakage of urine

Urinating more frequently can also appear with prostate problems. This is a condition that affects men. Usually men with prostate problems also notice that the urine stream is slow or hesitant. If you are seeing a urologist for your bladder problem, make sure he/she is aware that you have Parkinson's disease, because PD may provide an alternate explanation for the urinary problem. Urinary problems related to PD would not improve with surgical operations on the prostate.

Why does this happen?

Hyperactive bladder is related to numerous areas of degeneration in PD, including the nerve cells that control the bladder directly, the motor areas affected in PD, and sometimes the higher-level control of urination, in the brain.

What can I do?

If you are having trouble with hyperactive bladder, try to schedule bathroom trips at regular intervals, especially if you know a bathroom may not be close by.

What are other possible treatments?

There are several options that decrease the urgency and frequency to urinate. Sometimes the medications for the motor symptoms of Parkinson's can help the bladder problem. Your doctor may also suggest anticholinergic medications (Oxybutynin, Tolteridone) or tiroprium chloride (Trosec). If you have memory problems or hallucinations and your doctor has prescribed you an 'anti-cholinergic' medication, there is a chance that these medications can make these symptoms worse. If so, stop these immediately and speak with your doctor.

Desmopressin, a nasal spray, is often recommended for nighttime urination. This drug reduces the formation of urine. A rare but dangerous side effect of this drug is low salt levels in the blood. If you start taking this drug, you will need routine blood tests.

KEY POINTS

- **One third of people with PD have bladder dysfunction**
- **The bladder is usually over-active**
- **Most common symptoms include: getting up to urinate at night, frequently passing urine and urgency to pass urine**
- **Treatment options: Anticholinergic medications or desmopressin**

Unexplained Pain



What is this?

Of course, people with Parkinson's can have other conditions that cause pain, such as arthritis, lower back pain, etc. However, pain without any explanation may be caused by Parkinson's. This pain can feel like stiffness, cramps, spasms or other muscle pain. Many people have different types of pain all at once. The legs are the most commonly affected area. Usually the pain feels like it is in the muscles. One third of people with Parkinson's have such pain.

Why does this happen?

The cause of pain in Parkinson's is not always clear. Often it is related to muscle rigidity, which is a primary motor sign of Parkinson's. Often it occurs when medications are 'wearing off'. Finally, Parkinson's may make you somewhat more sensitive to pain in general.

What can I do?

Sometimes people will find that stretching the muscles, massage, or warm baths will help. If the problem is still there after speaking with your doctor, try over-the-counter pain medications, such as acetaminophen (Tylenol). Do not take more than the recommended dose.

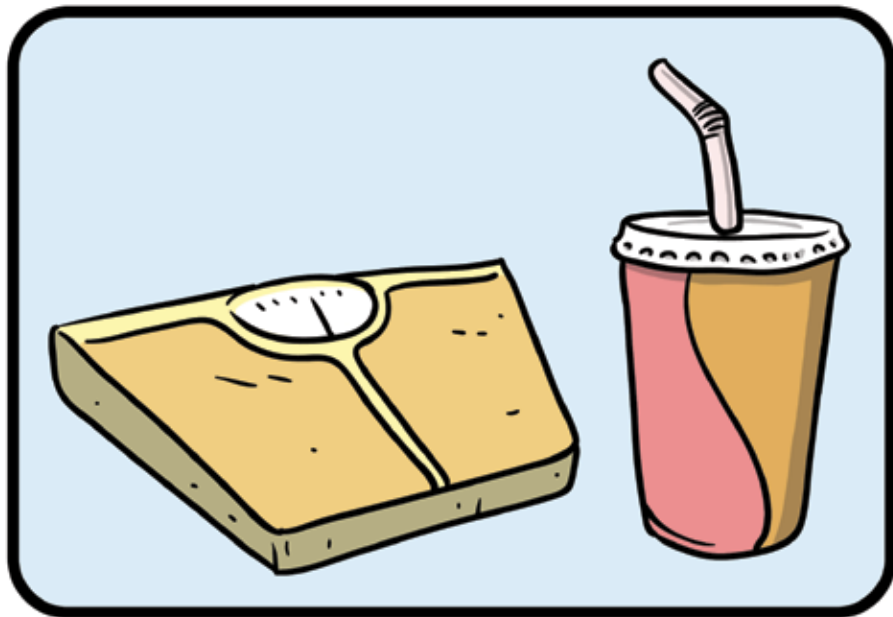
What are other possible treatments?

Severe pain is a clear sign that you should speak with your doctor. Pain is often a sign that treatment dosage should be increased. Many people have pain during 'off' periods (times when the medication is not working well). If this is your case, discuss with your doctor ways to decrease 'off' times. If pain continues to be a problem, your doctor may offer other pain medications.

KEY POINTS

- **One third of people with PD have unexplained pain**
- **Muscle aches and leg pains are the most common symptoms**
- **Increasing doses of Parkinson's treatments may help**
- **Treatment options: Over-the-counter pain medications if pain persists**

Unexplained Changes in Weight



What is this?

Changes in weight (gain or loss) can be experienced by people with PD. In general, weight loss is more common than weight gain.

Why does this happen?

The exact reason for changes in weight is not understood. Weight loss can be related to nausea from medications. It can also be caused by dyskinesia (excessive movements). Finally, it is a common feature in advanced PD - it is common for people with advanced disease to lose weight despite eating more.

Appetite is usually not increased in PD. However, excessive eating and weight gain after starting medications such as pramipexole (Mirapex) or ropinirole (Requip) can be due to an impulse control disorder (see section on impulse control disorders).

What can I do?

What are other possible treatments?

If nausea/vomiting are stopping you from eating, there may be treatments (see nausea section). Also, try taking meals during 'on' times (times when the medication is working well). You will find it easier to use utensils and you may also have less difficulties swallowing.

No medical treatment is used for weight loss due to PD. However, you should make sure that you are eating enough. If you are losing weight consistently, consider using milkshakes or calorie supplements (e.g. Ensure, Boost).

KEY POINTS

- **Unexplained increases or decreases in weight can happen in PD**
- **Treatment option: Try correcting any underlying problems (e.g. nausea). Also, eat during 'on' times.**

Cognitive Impairment & Dementia



What is this?

Mild cognitive impairment means a problem with memory or concentration that is bothersome but not enough to affect daily life. Dementia means a severe loss of memory/concentration enough to interfere with usual daily activities. Forgetting some information sometimes is normal as we age. It does not mean you have dementia or that you are cognitively impaired. When problems in memory and decision making impair your daily routine, they need to be addressed.

Common symptoms of cognitive impairment in Parkinson's include problems with attention and planning. Often, people are unable to follow a complicated conversation. Some notice trouble making decisions. It can also take a longer time to formulate thoughts. Solving complex problems can be a challenge. Memory can also be impaired. However, serious memory problems (as seen in Alzheimer's) are less common, and hints or clues are often enough to stimulate memory.

Why does this happen?

In most cases, dementia in Parkinson's occurs late in the disease, as the pathology starts to spread outside of the motor areas and into cognitive areas. It usually occurs in older people with Parkinson's (it is very rare below age 65).

What can I do?

There is some preliminary evidence that keeping yourself cognitively active might help prevent dementia. Exercise, good diet, good blood pressure control and prompt treatment of diabetes or elevated cholesterol may also help prevent dementia.

What are other possible treatments?

Medications are available to help with cognitive function. These include the 'cholinesterase inhibitors,' such as rivastigmine (Exelon) and donepezil (Aricept). These medications help a small or moderate amount. Common side effects include: nausea, vomiting, diarrhea and upset stomach.

Medications used to treat other features of Parkinson's or problems with sleep and anxiety occasionally worsen cognitive function (e.g. atropine, oxybutynin, nortryptiline, sedatives). Therefore, make sure your doctor knows all the medications you are taking.

KEY POINTS

- **Dementia or cognitive impairment may occur with advanced Parkinson's**
- **Common symptoms include: difficulty with planning, focussing attention, slowing of thought, decreased memory**
- **Some forgetfulness can occur normally with aging. However, it should not interfere with your daily routine**
- **Some medications can cause cognitive impairment**
- **Treatment option: 'Cholinesterase Inhibitors', like rivastigmine and donepezil, can improve cognitive impairment**

Hallucinations



What is this?

Hallucinations are not vivid dreams, disorientation, or abnormal beliefs. Hallucinations mean hearing or seeing things that are not really there.

In Parkinson's, hallucinations are almost always visual (you see something that is not there). They commonly begin as minor, non-threatening visual images. For example, a spot on the floor or the wall may move. Or the spot may look like an insect. If hallucinations progress, you may see children, animals or miniature people. At first, most people are aware that the hallucinations are not real. Later on, what is real may become blurred.

Why does this happen?

Hallucinations usually occur after years of having Parkinson's. They affect one third of people with the disease. They are partially related to medications, and partially related to disease affecting areas of the brain involved in interpretation of visual images.

What can I do?

Not all hallucinations need to be treated. You might be afraid to talk about your hallucinations. However, it is important to discuss them with your doctor, as they can often be helped.

What are other possible treatments?

If hallucinations are a problem, your doctor may try reducing some of your medications. If this makes motor symptoms worse or does not help, your doctor may prescribe quetiapine (Seroquel) or clozapine (Clozaril). These medications can sometimes make you sleepy. Other options include cholinesterase inhibitors. These are also used for dementia (see Cognitive Impairment & Dementia section).

KEY POINTS

- **One third of people with Parkinson's have hallucinations**
- **Hallucinations are almost always visual (you see things that are not there)**
- **Treatment options: Reducing medications, clozapine, quetiapine, rivastigmine or donepezil**

Depression & Anxiety



What is this? Why does this happen?

If you are depressed, you may not be able to experience joy. You may stop hobbies that you once enjoyed, and you may not want to carry out your daily routine. Learning new things may also not interest you. Fatigue is commonly linked with depression, but this is rarely the only symptom (fatigue often occurs by itself in Parkinson's). Depression can be an early sign of the disease. Although living with Parkinson's can certainly cause stress and sadness, depression may also be caused by changes in areas of the brain that affect mood.

Anxiety often occurs with depression in Parkinson's. Some people have bursts of anxiety called 'panic attacks.' Or you can have excessive worry about everyday things that you cannot control. As with depression, anxiety can be an early sign of Parkinson's. Anxiety is also common during 'off' periods.

What can I do?

One set of important protectors from depression is friends and family – as much as you can, keep yourself active and engaged with others. Exercise, particularly while outside, may help.

What are other possible treatments?

In some cases, you may find it useful to speak with a psychologist or other mental health professional. Certain types of psychological therapy (the commonest being called 'cognitive behavioral therapy') have been shown to help depression, although they have not yet been proven to help depression in Parkinson's.

Medications that have been shown to help depression in Parkinson's are nortriptyline and citalopram (Celexa). Nortriptyline has to be used with caution in people with memory problems or hallucinations, since it can worsen these symptoms.

KEY POINTS

- **One third of people with Parkinson's can experience anxiety and depression**
- **Parkinson's disease affects areas of the brain that control mood**
- **Depression and anxiety can begin before motor symptoms**
- **Anxiety can occur in 'off' periods. This can be improved by preventing the 'off' times.**
- **Treatment options: nortriptyline or citalopram**

Sexual Dysfunction



What is this?

With Parkinson's, some sexual dysfunction is common. In men, it can be hard to obtain or maintain an erection. Problems with having an orgasm or decreased sex drive can also occur. Women can have decreased interest in sex. Or they can have problems reaching orgasm. Sometimes an increase in sex drive can occur after starting a new drug.

Why does this happen?

Many other conditions can cause these symptoms. Difficulty with erection can be caused by diabetes, high blood pressure or being overweight. Women often have less sex drive after menopause. Abnormally increased sex drive can be due to an impulse control disorder related to medications (see page 51).

What can I do?

Regular exercise helps develop stamina for sexual intercourse. Also, you may want to consider other forms of intimacy. Speak with your partner and decide what is best for your relationship.

What are other possible treatments?

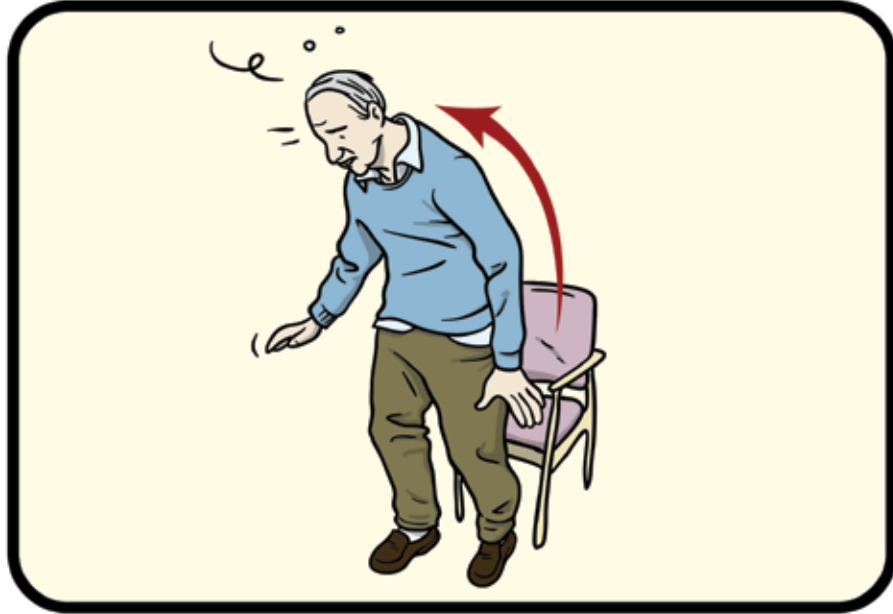
Some couples are not interested in having sex. In that case, you may not require any treatment. If sex interests you or your partner, talk to your doctor. Help is available.

Treatment for men includes sildenafil (Viagra) for erection problems. Testosterone is sometimes used for sex drive problems. Hormone replacement therapy can increase sex drive in women, but this comes with risks. Consult your doctor before starting any medications for erectile dysfunction or hormonal replacement therapy.

KEY POINTS

- **One half of people with Parkinson's have sexual dysfunction**
- **Sexual dysfunction can include: Difficulty with erections (men) or orgasm (women), or decreased sex drive (both men and women)**
- **Treatment option for men: Medications such as sildenafil**
- **Treatment option for women: Hormone replacement therapy, with caution**

Orthostatic Hypotension



What is this?

Orthostatic hypotension (OH) is a drop in blood pressure when standing. The most common symptom is light-headedness or dizziness when standing up from sitting. Confusion, headache, and shoulder/neck pain can also occur. If OH is severe, you could black out and fall.

Why does this happen?

Certain Parkinson's medications can worsen OH but they do not cause OH. OH is part of the disease process itself – areas that increase blood pressure with standing degenerate in Parkinson's.

What can I do?

If you have OH, avoid standing up quickly. Try elevating the head of the bed when you sleep. Slightly increasing salt intake and wearing compression stockings also can help.

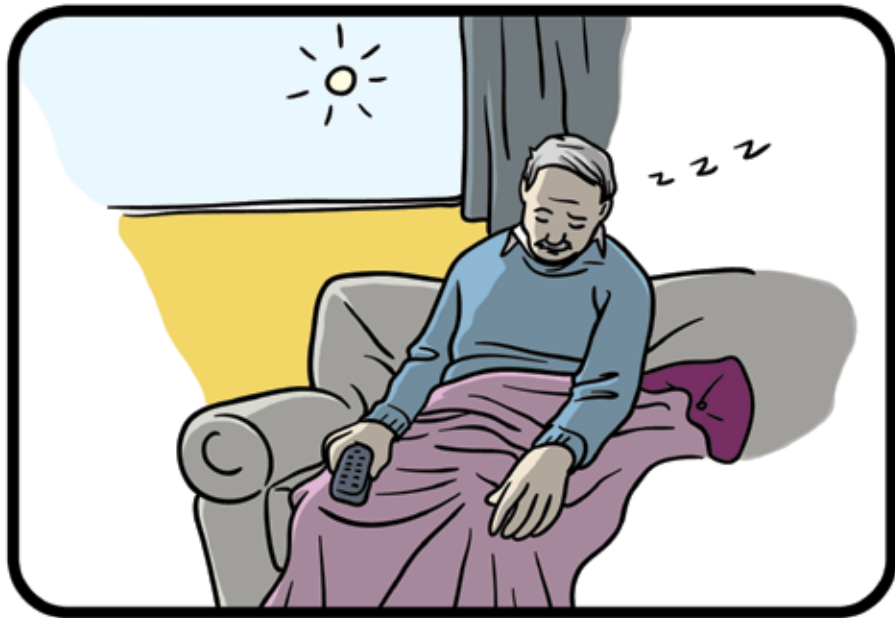
What are other possible treatments?

Most people with severe OH will need medications. Treatment options include: domperidone (see Nausea section), fludrocortisone and midodrine. The most common side effect of fludrocortisone and midodrine is high blood pressure when lying down. Physostigmine is another option, which also treats constipation.

KEY POINTS

- **One third of people with Parkinson's have orthostatic hypotension**
- **Main symptom: Feeling light-headed when standing up**
- **Other symptoms include: Confusion, pain, headache or blacking out when standing up**
- **Treatment options: Domperidone, fludrocortisone, midodrine or physostigmine**

Excessive Daytime Sleepiness



What is this?

Excessive daytime sleepiness means 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 a more severe case, you may have 'sleep attacks.' With a sleep attack you will have a sudden desire to sleep. This can occur while eating, working, walking or reading. You may even have sleep attacks while driving.

Why does this happen?

Many factors can make you sleepy. For example, it is a common side effect of Parkinson's medications. Poor sleep at night can also make you sleepy during the day (although that is usually not the problem). In addition, Parkinson's causes changes in brain areas that control sleep.

What can I do?

You may wish to try drinking extra coffee or tea during the day. Always avoid driving or operating heavy machinery if you feel even slightly sleepy.

What are other possible treatments?

Treatment often begins by reducing medication dosage. However, this can increase your tremor and slow your movements. Your doctor can also prescribe modafinil. This drug increases alertness. Common side effects of modafinil include headaches and nausea.

KEY POINTS

- **One half of people with Parkinson's feel sleepy during the day**
- **You may fall asleep while reading, talking or working**
- **Always think twice about driving, even if you are just a little bit tired**
- **Treatment options: Caffeine, adjustment of medications or modafinil**

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.

Why does this happen?

Occasionally, PD medications can also cause insomnia. Selegiline is the drug most likely to cause insomnia, especially if taken in the evening. However, the main reason for insomnia is changes in the brain caused by Parkinson's.

What can I do?

The first step you should take to treat insomnia is 'sleep hygiene.' Sleep hygiene includes:

- Bedtime and waking time should be as regular as possible
- Do not spend over 8 hours in bed
- Do not lie in bed for more than half an hour if you cannot sleep. Get up and do something relaxing. Then try to sleep again later.
- Bright light in the morning and exercise during the day
- Use your bed for sleep and sex only
- Reduce naps during the day

What are other possible treatments?

Insomnia can be very difficult to treat. Sleeping pills such as triazepam or temazepam may help. However, sleeping pills have side effects, especially feeling sleepy throughout the day. Always try sleep hygiene first. Then talk about other treatment options with your doctor. In many cases, it is best to not use medication.

KEY POINTS

- **With insomnia you may have difficulty falling and staying asleep**
- **Insomnia contributes to feeling tired during the day**
- **Treatment options: Try sleep hygiene or medications (rarely)**

REM Sleep Behaviour Disorder



What is this & Why does this happen?

REM (rapid eye movement) sleep is one of the five stages of sleep. Most dreaming occurs during this stage. Normally, there is no movement during REM sleep (you are paralyzed). If you have REM sleep behaviour disorder (RBD), this normal paralysis is lost.

RBD may cause you to act out your dreams. You may punch, kick, shout, talk or fall out of bed during this stage. You may end up injuring yourself or your bed partner. RBD occurs most often in the early morning (when people have the most REM sleep). You may have experienced RBD before developing the motor symptoms of Parkinson's.

What can I do?

If RBD is mild, no treatment may be needed. If you are having very active and severe movements, think about safety in bed – bed rails, pillows or mattresses beside the bed, etc. If there are violent movements, you may need to sleep apart from your partner until your RBD is treated.

What are other possible treatments?

If RBD becomes a problem, the main treatments are melatonin (3 mg at bedtime) or clonazepam (Rivotril). These medications are quite effective and have few side effects in low doses. Melatonin is the natural hormone of sleep and is available over the counter.

KEY POINTS

- **One third of people with Parkinson's have RBD**
- **With RBD, dreams are acted out. This includes: screaming, kicking, punching, thrashing etc.**
- **Injuries may occur**
- **Treatment options: Melatonin or clonazepam**

Restless Leg Syndrome



What is this?

Restless leg syndrome (RLS) is an urge to move the legs, often with pain or difficult to describe uncomfortable sensations. Generally, this is felt when sitting or lying down. RLS is worse in the evening and at night. Movement provides temporary relief. If you have RLS, you will feel the need to move your legs in the evening. This may cause trouble falling asleep.

Why does this happen?

One in ten people with PD will have RLS. This is similar to the number in the general population. However, RLS may be more severe in people with Parkinson's, perhaps related to use of medications for Parkinson's.

What can I do?

Generally, it is hard to treat RLS without medications. If mild, people can find that a brief walk around the room, or reading for a while can help.

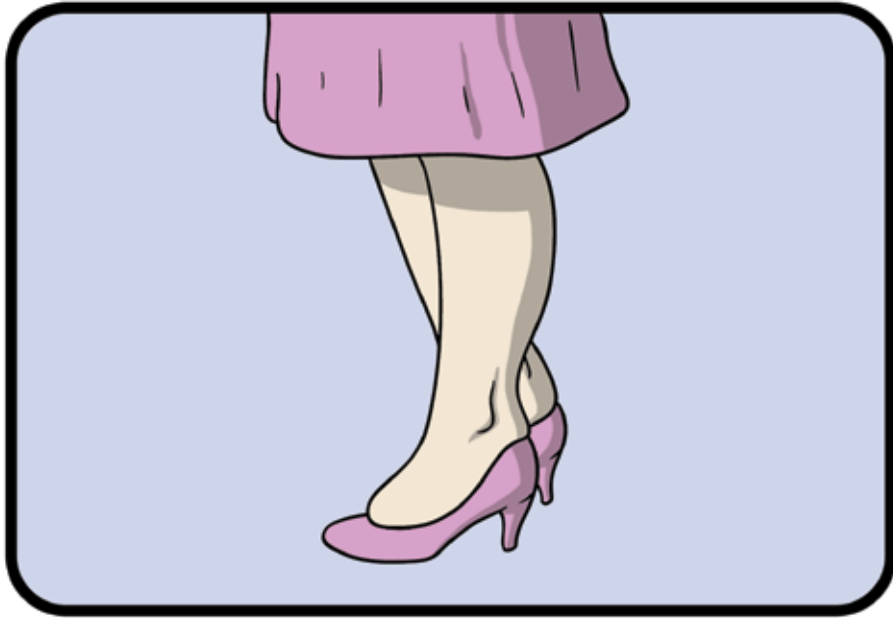
What are other possible treatments?

Medications used to treat Parkinson's also treat RLS. Levodopa, pramipexole (Mirapex), and ropinirole (Requip) taken at night may improve RLS. If your symptoms occur daily and are more severe, one option is gabapentin (Neurontin). This is not a Parkinson's drug. The most common side effect of this drug is feeling sleepy. Also, try to avoid caffeine, nicotine and alcohol at bedtime. These make RLS worse in some cases. Your doctor may suggest checking your iron levels in the blood, since low iron can cause RLS.

KEY POINTS

- **One in 10 people with Parkinson's have RLS**
- **With RLS, you feel an urge to move legs because of uncomfortable or odd feelings**
- **RLS tends to be worse at night and affects sleep**
- **Treatment options: Levodopa, pramipexole, ropinirole or gabapentin and avoidance of bedtime caffeine, nicotine and alcohol**

Leg Swelling



What is this?

Leg swelling is a common symptom in people with PD. Leg swelling means that the lower part of the legs often become bigger, and seem to be 'filled with water'.

Why does this happen?

Legs can swell as a side effect of Parkinson's treatments - levodopa, pramipexole (Mirapex) and ropinirole (Requip) cause leg swelling in 2-10 percent of users. Parkinson's disease itself can cause your legs to swell even without medications. It is important to note that many other medications, conditions affecting the heart, etc can also cause leg swelling. Therefore, it is important to make sure that there is not another cause.

What can I do?

What are other possible treatments?

When leg swelling is caused by Parkinson's, it tends not to be dangerous, and is usually not treated. Some people find compression stockings helpful – these are available at most pharmacies. Sitting with your legs up can also help. If the leg swelling is bothersome, speak to your doctor, as it could resolve with medication changes.

KEY POINTS

- Some people with Parkinson's have swollen legs
- Swelling can be caused by Parkinson's itself or by treatment
- Other conditions can cause leg swelling (e.g. heart disease)

Excessive Sweating



What is this?

Excessive sweating is found in one third of people with Parkinson's. With excessive sweating, you may find yourself sweating with no exercise, or sweating profusely with mild exercise.

Why does this happen?

The exact reason for this symptom is not known. Excessive sweating commonly occurs when your muscles are stiff (i.e. during 'off periods'). It also occurs during dyskinesia (excessive movements as a side effect of medications).

What can I do?

There is no specific treatment for excessive sweating. However, you can help limit the amount that you sweat. Try these steps:

- avoid hot or humid environments
- avoid strenuous activity in the heat
- set the house thermostat lower
- wear appropriate clothing
- always keep well hydrated

What are other possible treatments?

Usually, excessive sweating is not a disabling problem, and medications are not helpful. However, it is important to monitor when excessive sweating occurs. If it occurs when your medications are wearing off, this is important information for the doctor, and may result in medication changes, particularly with timing of pills.

KEY POINTS

- One third of people with Parkinson's develop excessive sweating
- Sweating is often associated with 'off periods' or dyskinesias (excessive movement)
- Some practical tips can help (see above)

Double Vision



What is this?

Double vision is when you see two images of the same object. It is an uncommon symptom of Parkinson's. Most often, double vision with Parkinson's happens while reading.

Why does this happen?

There are many other causes for double vision besides Parkinson's. In Parkinson's, double vision is usually caused by the eye muscles being underactive (just like the rest of the muscles in your body).

What can I do?

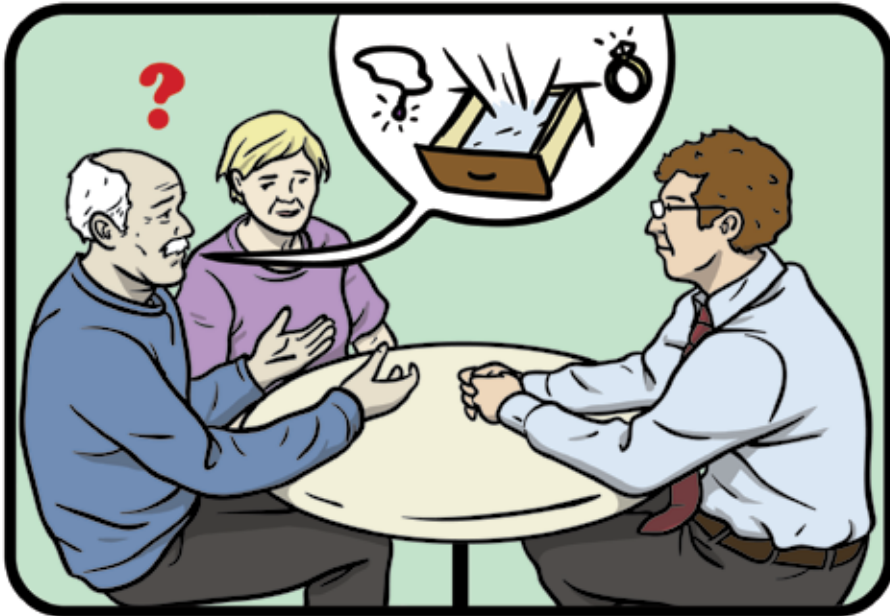
What are other possible treatments?

The medications used to treat Parkinson's (levodopa, pramipexole etc.) may help with double vision, by increasing the muscle activity to the eyes. Talk to your doctor about this problem - you may need to visit an ophthalmologist (eye specialist) to rule out other causes.

KEY POINTS

- Double vision is when you see two images of a single object
- Double vision is fairly uncommon
- Many other conditions can cause double vision
- Treatment option: Increasing Parkinson's medications can sometimes help

Delusions



What is this?

Delusions are false beliefs that are not based on reality or fact. Delusions may occur after having hallucinations. Suspicions are most often directed at family members. Common delusions include cheating spouses or theft. Delusions mainly occur in advanced Parkinson's.

Why does this happen?

Typically, delusions occur in people who also have cognitive impairment, and are therefore part of advanced PD. Often, Parkinson's medications can make delusions worse.

What can I do?

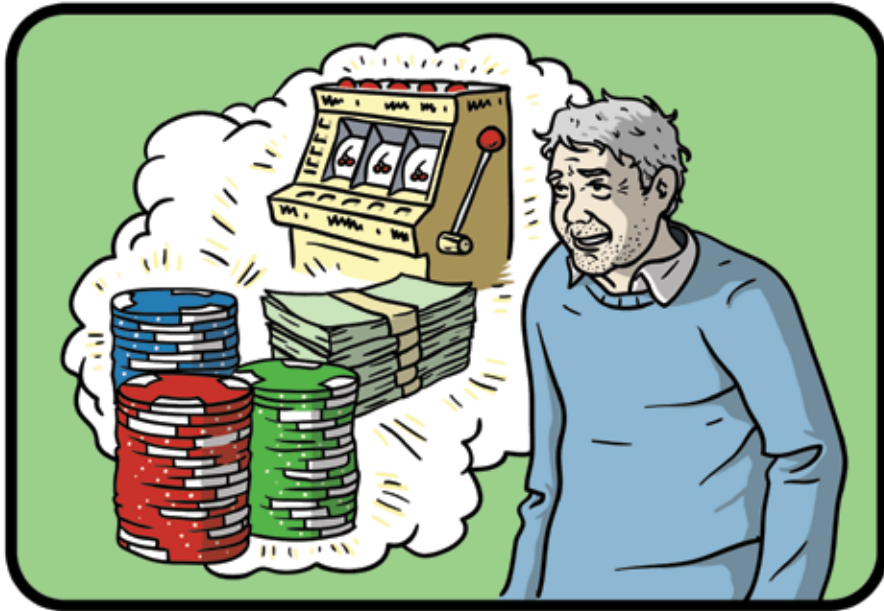
What are other possible treatments?

Speak to your doctor. The same treatments that are used for hallucinations can help delusions (decreasing certain Parkinson's medications, clonazapine and quetiapine, acetylcholinesterase inhibitors).

KEY POINTS

- Delusions are uncommon
- Delusions often include cheating spouses and theft
- Treatment options: Decreasing medications; clonazapine and quetiapine

Impulse Control Disorders



What is this?

About one in eight people on Parkinson's medications may develop impulsive, uncontrolled behaviour. Impulsive, uncontrolled behaviours, or 'impulse control disorders' (ICD), can include:

- excessive gambling
- hypersexuality
- binge eating
- compulsive shopping
- punding (repetitive performance of meaningless tasks).

You are especially at risk for ICD if you have a history of alcohol abuse, gambling or addiction. However, ICD can happen to anybody with PD.

Why does this happen?

ICD symptoms are usually a side effect of medications. Dopamine agonists pramipexole (Mirapex) and ropinirole (Requip) are the medications that carry the most risk for developing ICD.

What can I do?

Those around you should be made aware of the possibility of ICD. This way they can contact help as needed. If ICD is a problem, the most important thing is to inform your doctor.

What are other possible treatments?

Since this is usually a side effect of medications, your doctor will usually reduce your treatment dosage. This usually solves the problem. When medications are stopped or reduced, motor symptoms can become worse, so you and your doctor will have to balance side effects with benefits.

KEY POINTS

- **One in eight people on certain Parkinson's medications have an impulse control disorder (ICD)**
- **Excessive gambling and hypersexuality are the most common ICDs**
- **Treatment option: Treatment dosage is usually decreased**

Notes

Lined area for taking notes, consisting of 20 horizontal blue lines.

PD NMS QUESTIONNAIRE

Name:

Date:

Age:

Male Female

NON-MOVEMENT PROBLEMS IN PARKINSON'S

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it **during the past month**. The doctor or nurse may ask you some questions to help decide. If you have **not** experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

Have you experienced any of the following in the last month?

- | | Yes | No | Yes | No |
|---|--------------------------|--------------------------|--|--------------------------|
| 1. Dribbling of saliva during the daytime | <input type="checkbox"/> | <input type="checkbox"/> | 16. Feeling sad, 'low' or 'blue' | <input type="checkbox"/> |
| 2. Loss or change in your ability to taste or smell | <input type="checkbox"/> | <input type="checkbox"/> | 17. Feeling anxious, frightened or panicky | <input type="checkbox"/> |
| 3. Difficulty swallowing food or drink or problems with choking | <input type="checkbox"/> | <input type="checkbox"/> | 18. Feeling less interested in sex or more interested in sex | <input type="checkbox"/> |
| 4. Vomiting or feelings of sickness (nausea) | <input type="checkbox"/> | <input type="checkbox"/> | 19. Finding it difficult to have sex when you try | <input type="checkbox"/> |
| 5. Constipation (less than 3 bowel movements a week) or having to strain to pass a stool (faeces) | <input type="checkbox"/> | <input type="checkbox"/> | 20. Feeling light headed, dizzy or weak standing from sitting or lying | <input type="checkbox"/> |
| 6. Bowel (fecal) incontinence | <input type="checkbox"/> | <input type="checkbox"/> | 21. Falling | <input type="checkbox"/> |
| 7. Feeling that your bowel emptying is incomplete after having been to the toilet | <input type="checkbox"/> | <input type="checkbox"/> | 22. Finding it difficult to stay awake during activities such as working, driving or eating | <input type="checkbox"/> |
| 8. A sense of urgency to pass urine makes you rush to the toilet | <input type="checkbox"/> | <input type="checkbox"/> | 23. Difficulty getting to sleep at night or staying asleep at night | <input type="checkbox"/> |
| 9. Getting up regularly at night to pass urine | <input type="checkbox"/> | <input type="checkbox"/> | 24. Intense, vivid dreams or frightening dreams | <input type="checkbox"/> |
| 10. Unexplained pains (not due to known conditions such as arthritis) | <input type="checkbox"/> | <input type="checkbox"/> | 25. Talking or moving about in your sleep as if you are 'acting' out a dream | <input type="checkbox"/> |
| 11. Unexplained change in weight (not due to change in diet) | <input type="checkbox"/> | <input type="checkbox"/> | 26. Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move | <input type="checkbox"/> |
| 12. Problems remembering things that have happened recently or forgetting to do things | <input type="checkbox"/> | <input type="checkbox"/> | 27. Swelling of your legs | <input type="checkbox"/> |
| 13. Loss of interest in what is happening around you or doing things | <input type="checkbox"/> | <input type="checkbox"/> | 28. Excessive sweating | <input type="checkbox"/> |
| 14. Seeing or hearing things that you know or are told are not there | <input type="checkbox"/> | <input type="checkbox"/> | 29. Double vision | <input type="checkbox"/> |
| 15. Difficulty concentrating or staying focussed | <input type="checkbox"/> | <input type="checkbox"/> | 30. Believing things are happening to you that other people say are not true | <input type="checkbox"/> |

