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.
Symptoms can usually be controlled or reduced. There are many medications and strategies that can help. This booklet is meant to be a general guide. Not everyone will have all of these symptoms. You may have different symptoms than someone else or experience less common symptoms not discussed here. Speak to your treatment team. This will help them 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.
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 what 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 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.

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?

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.

What are other possible treatments?

There is no treatment for changes in taste and smell.

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 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.

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.

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.

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 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.

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 therapy. Constipation can be the first symptom of Parkinson’s. You may have noticed it years before you had motor problems.

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.

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 agent, 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. Diapers for problems such as this are available.

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 cerebral cortex.

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 trospium 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 disease - 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?
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 (like 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, nortryptyline, 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 means 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