

TraPCAf & Parkinson's Africa Virtual Support Group Series 2024

Parkinson's Disease (Non-Motor) Symptoms.

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From Newcastle. **For the world.**

Introduction

Parkinson's Disease is a neurodegenerative disorder whose most prominent symptoms are muscular including rigidity, tremors and slowness and Symptoms associated with Nervous System, Alimentary Canal, Cardiovascular System and Respiratory System. PD is primarily due to the insufficient formation of Dopamine which is produced in the dopaminergic neurons of the brain.

SYMPTOMS PREGRESSION

It's important to remember that the way symptoms progress will be different for everyone and most people will only experience some of them.

Many people have already had Parkinson's diseases for years by the time they are diagnosed or have had symptoms that were progressing toward it with tremors being especially common prior to diagnosis.

So as Parkinson's diseases progresses the most troublesome symptoms change considerably including dependency.

Some common Non-motor symptoms of PD are as discussed below.



1. NERVOUS SYSTEM

The nervous system is made up of the brain, the spinal cord, the nerves and the sense organs such as the eye and the ear. The nervous system receives, intercepts and responds to stimuli from inside and outside the body. In Parkinson's Disease there can be a likelihood of depression, dementia, pain, fatigue, sleep disturbance, anxiety, vertigo, apathy, anhedonia, bradyphrenia, alexithymia as discussed below:

A. Depression

Depression is usually diagnosed when you have feelings of extreme sadness or a sense of emotional 'emptiness' for a long time. It's more than temporary feelings of sadness, unhappiness or frustration. These feelings may affect your ability to carry out day-to-day activities.

Cause - In Parkinson's Disease, reduction of dopamine can trigger depression, also the news of PD diagnosis can as well trigger depression together with the thoughts that you won't be able to do most of the things normally.

Management - The feelings of depression can be well reduced or managed by both exercise and physical activities, relaxation therapy, quality sleep with a quiet and comfortable room. Some relies on antidepressants prescribed by their Neurologist.



B. Dementia

Thinking and memory changes can be a normal part of getting older, but they may affect you more if you have Parkinson's thus termed as dementia. Dementia can begin as mild cognitive impairment and then gradually develop in to Parkinson's Disease Dementia. **Parkinson's dementia** is very similar to another type of dementia, called **dementia with Lewy bodies**.

The main difference is the timing of when you start experiencing symptoms. If you've had movement symptoms (such as tremor or stiffness) for at least one year before symptoms of dementia, specialists will often give a diagnosis of Parkinson's dementia.

If you get dementia symptoms before or at the same time as movement symptoms, specialists will usually give a diagnosis of dementia with Lewy bodies

They both share the same symptoms such as slowness in thinking, difficulties in visual and practical tasks like reading clock and putting clothes correctly and many more.

Cause - One of the reasons for this is that there are lower levels of a brain chemical called acetylcholine, as well as dopamine. Another cause is that proteins can build-up in the brain and affect different brain areas.

There is still a lot of research happening to understand the brain changes that cause thinking and memory symptoms in Parkinson's.



Practical tips on Dementia Management

Some people believe that nothing can be done about thinking and memory changes in Parkinson's. But that isn't the case. There are several important steps that people can take for themselves to improve and even slow thinking and memory changes, these includes:

- Having calendars, clocks, noticeboards in your home may help jog your memory
- Tackle one thing at a time this can reduce stress and help you feel in control
- Have a basket or box to keep things like your keys, wallet and glasses in one place
- Drug dispensers and pill timers can be a useful reminder to take your medication. Keep a diary of your symptoms
- Physiotherapy, [speech and language therapy](#), Occupational Therapy and also support from specialist mental health services, such as neuropsychology



C. Pain.

Pain is a common symptom in Parkinson's, affecting about 60% of people with the condition. There are different types of pain that can affect people with Parkinson's and a range of ways manage it.

Musculoskeletal (muscle) pain - This is the most common type of pain people with Parkinson's experience. It's related to Parkinson's rigidity and reduced movement of the joints. It usually feels like an ache in the neck and back, but any part of the body can be affected.

Dystonia-This type of pain is common in Parkinson's. It's caused by [involuntary muscle contractions](#) and for some people the pain can be severe.

Radicular (shooting pain)-This is felt as a sharp, often shock-like, shooting pain that travels down the arm or leg, and sometimes the fingers and toes too. Tingling and numbness in the toes and fingers is also common in people with Parkinson's.

Dyskinetic pain- This can be described as a deep, aching sensation. It can happen because of involuntary movements (dyskinesia) that some people with Parkinson's experience. It can also happen before, during or after movement.

By improving your general fitness the pain can be well managed together with the normal painkillers.



D. Sleep Disturbance

Sleep disorders in Parkinson's Disease include, insomnia, impaired bed morbidity, restless leg syndrome, sleep disordered breathing among others. All these makes sleeping difficult.

Parkinson's medication can cause excessive daytime sleepiness or sudden onset of sleep. This can be severe for some people, so it's important to get support from your healthcare professional if this happens.

Excessive feelings of sleepiness during the day can also happen if you aren't sleeping well at night. The effect can cause some people to doze off during normal waking hours.



E. Fatigue

People with Parkinson's Disease are prone to fatigue. Fatigue is an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. Cause-Many people with Parkinson's experience fatigue but it's common in people with other long-term physical health conditions too. Some of the causes of fatigue in PD are:

- **The timing and dosage of your medication.** This can mean that you feel energetic and capable of doing everyday jobs at certain times of the day, but not at other time
- **Tremors, stiffness and involuntary movements** which may put stress on your muscles.
- **Slowness in movement, bradykinesia,** If you experience this, tasks can take you longer to complete than they used to, leading to fatigue
- **Stress.** Parkinson's and its symptoms can cause stress at work or home and this can make fatigue worse, particularly true if stress builds up over a period of time
- **Sleep disturbance** also causes fatigue

Having a diary to monitor the timing and the cause of fatigue can help in management, be it, tremors ,stress, slowness and sleep disturbance also medication and physical exercise. Talk to the healthcare provider if the fatigue persists.



F. Anxiety

Anxiety is a feeling of unease, such as worry or fear, which some people with Parkinson's may experience mostly encountered during of after a stressful events. Anxiety is characterized by restless legs and difficulty maintaining restful sleep, constant worry, difficulty concentrating, dizziness trembling among others.

Management-Doctors uses anti-depressants in the management of anxiety, but if a person focuses on good diet excluding caffeine, staying active and practicing yoga or TaiChi the feeling of anxiety goes away.

G. HALLUCINATION AND DELUSION

Some people with Parkinson's may experience hallucinations or delusions and they are more common in advanced Parkinson's. **Hallucination** is when you see, hear or feel things that aren't there while **Delusions** are unusual thoughts, beliefs or worries that aren't based on reality. Usually, when people with Parkinson's experience hallucinations and delusions, it will be a side effect of their medication rather than a direct symptom of Parkinson's.

Management - It's important to get medical advice and review the dosage with your neurologist. The caregivers also should acknowledge the facts of these symptoms and try distract the affected person from it to bring them back to time. Anxiety may make hallucinations and delusions worse. Try to find ways to help the person relax such as talking to them calmly or taking them somewhere quiet to unwind.



2. ALIMENTARY CANAL SYSTEM

The alimentary canal system includes all the body structures involved in eating food, digestion and excretion. This includes oral cavity, pharynx, oesophagus, stomach, small and large intestine, rectum and anus. In Parkinson's disease there can be likelihood of constipation, dysphagia (swallowing difficulty), sialorrhea (drooling), gastro paresis (slow gastric emptying).

A. Constipation

Constipation is when your stools become hard and difficult to pass, or when you have bowel movements less frequently than you've had before. Constipation is common in people with Parkinson's. Some people don't recognise it as a problem because it has become 'normal' for them. Constipation can be caused by the following:

- Not drinking enough fluids.
- A lack of physical activity that helps in muscle movements.
- Not going to the toilet in time or not going to the toilet when you need to. The longer the stool remains in the body, the more fluid is reabsorbed through the bowel wall, making it dry. This can make it harder to push out stools.
- Medication. Some medication makes constipation worse. It might be your Parkinson's drugs or other types of medication including painkillers.

Management: Engage in Physical activity and exercise which stimulate your bowels and helps prevent constipation and contribute to stronger pelvic floor muscle. Increase fibre intake and take plenty of fluids during the day to avoid dehydration and more fruits.



B. Dysphagia (swallowing difficulty)

Some people with dysphagia have problems swallowing certain foods or liquids while others can not swallow at all. Dysphagia can cause coughing or choking when eating or drinking. People with Parkinson's Disease there is an increased contraction of the pharyngeal muscles which is responsible for swallowing.

Management

- Adjusting your sitting posture and head posture when eating or drinking
- Changing your diet to make food and liquid easier and safer to swallow. This may include avoiding hard, dry or crumbly food, moving on to softer, moist food, or thickening drinks to make them move more slowly in the mouth
- Avoiding taking mouthfuls of food or drink that have different consistencies together, like cornflakes and milk, or peas and gravy
- changing how you eat and drink, particularly the speed you eat and your mouthful size, to reduce the risk of coughing and choking
- See a speech therapist and dietician to formulate how best to handle dysphagia.

C. Sialorrhea (Drooling)

This is excessive salivation or failure to swallow caused by dysphagia because of excessive contraction of the pharyngeal muscles involved in swallowing. The management is same as in dysphagia. Also consider lip training exercises like closing your lips as tightly as possible and hold for a count of four, relax, then repeat five times, Stretch your lips in a wide smile, hold for a count of four, and relax, Purse your lips as if you're going to whistle or kiss someone, hold for a count of four, and relax.

Some people uses sweets and lollipop to engage their muscles in the mouth and ease swallowing of the saliva. A speech therapist also plays a bigger role in the management of dysphagia and drooling.



D. Gastro paresis

Gastroparesis, also called delayed gastric emptying, is a disorder that slows or stops the movement of food from your stomach to your small intestine, even though there is no blockage in the stomach or intestines. This due to impaired motility which causes an increased contraction of colon muscles.

The delayed gastric emptying can cause Early Morning Off. The muscles around the stomach, small gut and oesophagus are also affected do that there is reduced motility around them. Physical exercises and frequent fluid intake ease this muscles and make it comfortable for the gastric emptying.

3. URINARY SYSTEM

The urinary system consists of the two kidneys, ureter, the bladder and the urethra. In Parkinson's Diseases there is often **Nocturia,(frequent urinating at night)**-As you get older, it's normal to get up once or twice in the night to urinate. But nocturia is when there's a need to go more than once or twice at night, which may be because of an overactive bladder or an increase in urine production. This may wake you up, or your bladder may empty while you're asleep. If Parkinson's drugs have worn off during the night, it may be harder to get to the toilet in time if you have nocturia. , **Urinary incontinence(loss of urinary control)**-Urge incontinence is when you feel the need to urinate immediately, at times without warning. This means that you can't 'hold on' as you might do normally when you feel the urge to go. As a result, you might not reach a toilet in time.

Sometimes bladder problem can be due to bacterial infection which are treatable by antibiotics, also practice balance diet and bladder training by keeping record on how long you can hold urine. Talk to your doctor for better management..



4. CARDIOVASCULAR SYSTEM

Cardiovascular system consist of the heart and blood vessels of the body. In Parkinson's disease there are report of Hypotension(low blood pressure). It can be a symptom of Parkinson's or it can be a side effect of the drugs used to treat the condition like Levodopa, antidepressants. It may also be connected to another health condition.

Managing hypotension involves keeping record of the blood pressure and involvement with a cardiologist or neurologist on dispensed medication. Also being keen in the day to day activities, Bend or reach for things slowly and hold on to something if you need to. This will mean you don't lose your balance and fall over.

5. RESPIRATORY SYSTEM

Respiratory muscle dysfunction usually, but not always, occurs in Parkinson's disease. Larynx and tracheal muscles are involved in respiration. Increased vibration of these muscles reduces their functionality and strength which leads to limitation in breathing despite having the correct lung volume. Due to the reduced respiratory capacity, people with Parkinson's Disease are more prone to pneumonia and asthma.

Exercising your lungs, chest muscles and rib cage is important when you have Parkinson's because: your chest wall can become stiff, and the muscles weaker. This can make it harder to breathe or cough



Parkinson's Disease and Sexual issues

Our sexual response and function are controlled by our motor and autonomic nervous systems which are manageable by medication. However, medication can diminish sexual desire and reduce sexual response.

Besides Parkinson's Disease affecting the **motor**, some medications and **Non-motor** factors may also cause sexual problems.

They include:-

- Sleep difficulties
- Reduced self esteem
- Depression and grief
- Anger and stress
- Continence issues, constipation
- Urgent and frequent urination
- Pain and fatigue

Practical Suggestions for couples

- Learn about the effects Parkinson's and its treatment can have on sexuality
- Appreciate and recognize the emotional stress you are both going through
- Talk frankly and openly about sexual needs. Communication is the best remedy for all types of relationship problems.
- Experiment with different routines – for example, switch lovemaking to the morning when Parkinson's symptoms tend to be less pronounced or when you have better mobility (your 'on' time).
- Work together with medical staff to reduce the effects of medications on sexual function.



Impact of PD on PwP, Caregivers and Care partners.

Parkinson's disease symptoms can have a significant impact on individuals with the disease, as well as on their caregivers and care partners. Some common impacts include:

- 1. Physical limitations:** Symptoms such as tremors, stiffness, and difficulty with balance and coordination can make everyday tasks challenging for individuals with Parkinson's disease.
- 2. Emotional effects:** Parkinson's disease can also affect a person's mood and mental health, leading to feelings of depression, anxiety, and frustration.
- 3. Social isolation:** The physical and emotional challenges of Parkinson's disease can lead to social withdrawal and isolation, as individuals may struggle to participate in activities they once enjoyed.
- 4. Financial burden:** The cost of medical care, medications, and home modifications can play a significant financial strain on individuals with Parkinson's disease and their caregivers.
- 5. Caregiver burnout:** Caregivers and care partners of individuals with Parkinson's disease may experience physical and emotional exhaustion from the demands of providing care and support.

Generally, people with Parkinson's Disease, Caregivers and care partners needs an uttermost Phsco-education support.



Credit:

European Journal of Neurology(2011)-C.Becker, S.Johanson,S.S Jick

Parkinsonism and Related Disorders (2016)- J.Koerts, L.Tucha, O.Tucha

Lancet Neurology (2014)- A.Schrag, L..Horsfall,K.Walters.

The comprehensive Guide to Parkinsons Disease- keith brdgeman, Tahira Arsham



Thank you!

For more information and resources visit: www.parkinsonsafrica.org

Get in touch if you have a query: tania@parkinsonsafrica.org

Please complete the post session questionnaire!

