



UNDERSTANDING PARKINSON'S DISEASE

An Introductory Guide

By Parkinson's Africa and IPDGC-Africa

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This booklet has been put together for informational and educational purposes only. It should not be interpreted to be a diagnosis, treatment or any other type of health care advice. The reader should seek their own medical or professional advice and must not rely on the information contained in this booklet as an alternative to medical advice from their doctors or other professional healthcare providers. The producers, distributors and sponsors of this booklet disclaim any responsibility and liability of any kind in connection with the reader's use of the information contained here.

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Live Empowered!

Parkinson's Disease in Africa

Parkinson's disease (PD) is the second most common neurological disorder (after Alzheimer's) in the world, and it is currently the fastest growing – with cases across Africa expected to rise significantly in the coming years. With this projected increase comes an even greater need to address the lack of awareness, misconceptions and stigma surrounding PD in Africa.

The production of this booklet is part of a larger initiative – the **S.E.E. Parkinson's** health literacy campaign, put together by Parkinson's Africa and IPDGC-Africa, to address the scarcity of relevant educational and informational PD resources in Africa. To learn more about the initiative, or to access other translations of this booklet, please visit **www.parkinsonsafrica.org** or **www.ipdgc-africa.com**.

If you have PD or are looking to learn more about the disease, this booklet was put together for you. We understand that being diagnosed with PD can be an emotional and scary experience for some, but we believe that being equipped with the right information is the best way to fight back. This booklet is one of several resources we have put together to help you fight back. For additional PD information and resources, please visit **www.parkinsonsafrica.org**.

What is Parkinson's disease?

Parkinson's disease, or simply Parkinson's, was described by Dr. James Parkinson, from London, in 1817; it is a chronic (lifelong) disease of the brain that slowly gets worse over time.



It mainly affects the substantia nigra – the part of the brain that is responsible for controlling movement. This affected region of the brain also plays a role in other important functions such as learning, behaviour, sleep, pain and memory. Parkinson's may also affect other parts of the body such as the bowel, the bones and the eyes.



Parkinson's Si Buko – A Parkinson's health clinic in Uganda

What causes Parkinson's?

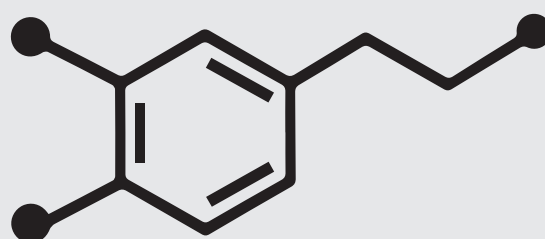
Parkinson's happens when the cells that produce the brain chemical, dopamine, stop working properly and die prematurely. Other chemicals in the brain are also involved. Researchers are not certain what causes this to happen, but they suspect that genetic factors (like gene mutations) and environmental factors (like exposure to toxic chemicals), in addition to the ageing process, play an important role.

Obeng Amoako
(Ghana)
Diagnosed at 60



How do I know if I have Parkinson's?

A person with Parkinson's may experience some of these symptoms – tremor, stiffness, loss or reduced sense of smell, constipation, difficulty sleeping and small handwriting – but there could be more. During the early stages of the disease, many of these symptoms are usually mild and may even go unnoticed. If you are worried that you or a loved one may have Parkinson's, it is important to speak with a health expert to get a proper diagnosis.



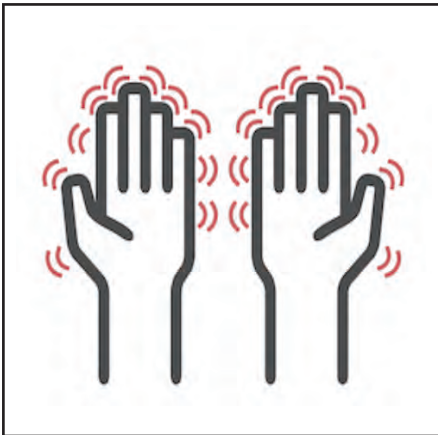
Dopamine

What are the symptoms of Parkinson's?

Parkinson's is characterised by **motor symptoms** (those that affect movement) and **non-motor symptoms** (those that do not affect movement).

Motor symptoms

The three primary motor symptoms of Parkinson's are tremor, slow movement and rigidity. Although very common, it is important to note that not everyone with Parkinson's will experience these symptoms.



Tremor



Slow Movement



Rigidity

Tremor:

Uncontrollable shaking of a part of the body such as the hands, jaw, lips or legs. It starts on one side of the body and usually occurs when the affected body part is at rest.

Slowness of movement:

Also known as "bradykinesia", this symptom is characterised by very slow movements, making it difficult to perform tasks like walking and tying shoelaces.

Rigidity:

Stiffness in the muscles that creates difficulties with movements like swinging your arms or turning around in bed.

Other motor symptoms

Other motor symptoms of Parkinson's include reduced facial expression, dystonia (uncontrolled and painful muscle cramps), improper posture (the body may stoop forward or sideways), walking abnormalities such as dragging the feet, balance issues and handwriting that becomes smaller and smaller.

Non-motor symptoms

Parkinson's disease also has a wide range of non-motor symptoms. Researchers have discovered that some of these symptoms, like reduced sense of smell and constipation often appear many years before the onset of motor symptoms. Some common non-motor symptoms are:

Cognitive Difficulties

These include difficulties focusing, paying attention, planning, doing multiple things at the same time, organizing and remembering things.

Mood Disorders

Apathy (lack of interest), anxiety (feeling worried and scared), depression (feeling sad) and irritability (easily bothered and upset).

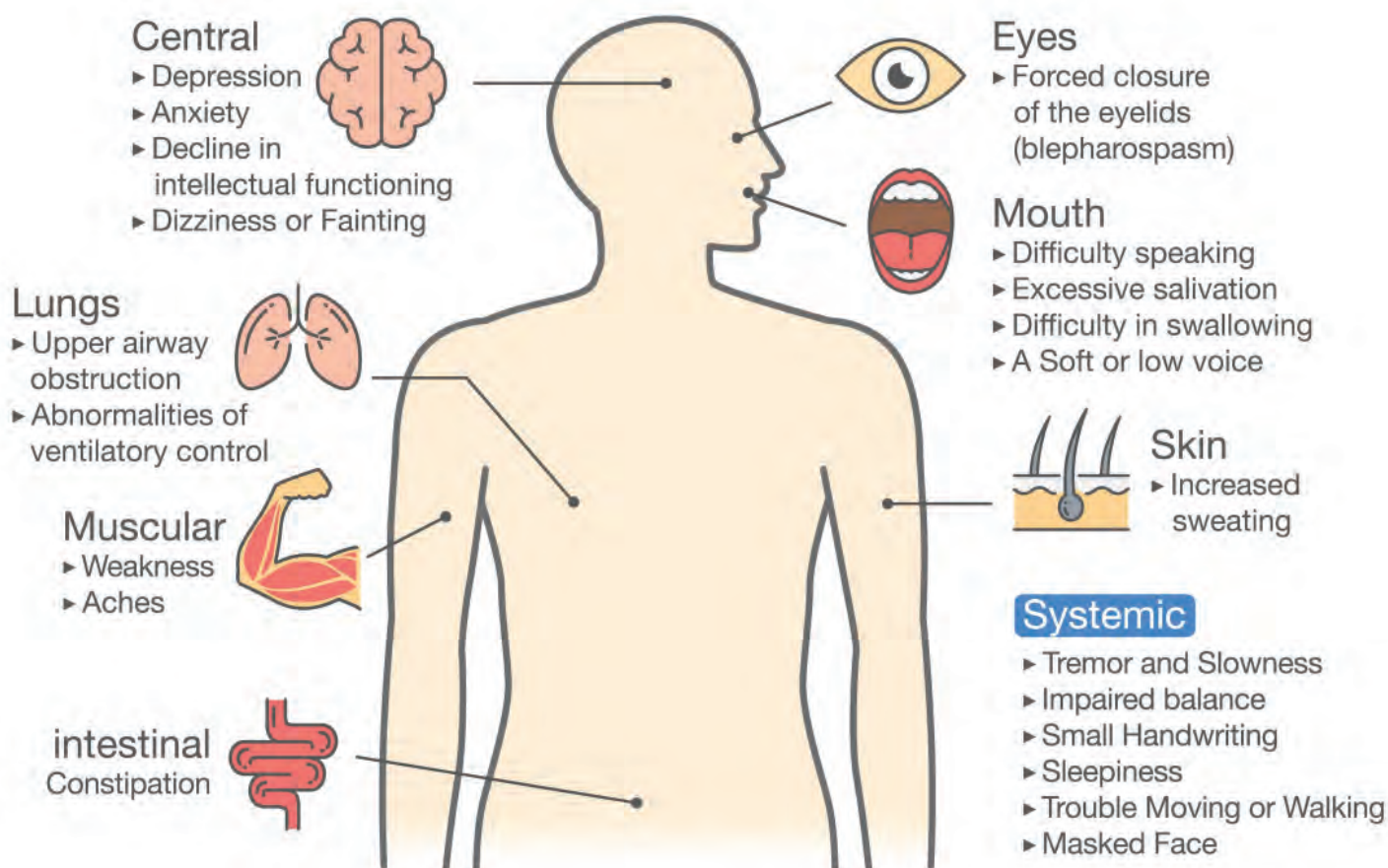
Sleep Disorders

Insomnia (trouble falling asleep), disturbances during sleep, acting out dreams and excessive daytime sleepiness.

Other non-motor symptoms

Other non-motor symptoms include pain, fatigue (feeling tired), constipation, a drop in blood pressure when standing, reduced sense of smell, urinary problems, vision problems, hallucinations (usually occurs in the later stages of the disease due to medications) and, for some people, impulse control disorders also caused by some medications (this could include excessive urge to buy things, gamble or high sex drive).

If you are experiencing any (or a combination) of these symptoms, it is important to see a health expert to rule out other health conditions with similar symptoms as Parkinson's.



Common symptoms of Parkinson's

Who is at risk of getting Parkinson's?

Increasing age is the biggest risk factor for developing Parkinson's, and most people who get the disease are around 60 years or older. Parkinson's, however, is not a respecter of age, and people who are much younger can get it as well.

Does Parkinson's run in families?

Most people have what is called "idiopathic" Parkinson's, meaning the cause is unknown. It is possible (although very uncommon) for people to pass Parkinson's on to their children. However, specific genetic tests to predict this are not available at this time.

Is Parkinson's contagious?

No, Parkinson's is not contagious. It can not be spread through close contact with an affected person.

How does Parkinson's disease progress?

This will be different for each person, but generally speaking, Parkinson's progresses gradually, with symptoms slowly getting worse over time. In the earlier stages of the disease, many people are able to carry out their daily functions as normal.

Is Parkinson's fatal?

Parkinson's is not a fatal illness, and most people's life expectancy will not change as a result of their diagnosis (provided they receive appropriate care and treatment). However, some of the more advanced symptoms can lead to increased disability and poor health.

How is Parkinson's diagnosed?



Parkinson's is usually diagnosed by a neurologist (a doctor who deals with conditions affecting the brain, nerves and spinal cord), a geriatrician (a doctor who specialises in the care of older adults) or a specialist physician. While there is currently no specific Parkinson's test, your doctor can make a diagnosis after reviewing your medical history, evaluating your symptoms, and conducting a series of simple assessments where you may be asked to perform activities like tapping your fingers, standing from a chair, walking, writing or speaking.

Dr. Vida Obese

Specialist Physician, KATH
Kumasi, Ghana.

A favourite quote of mine is "It's not what happens to you that determines how far you go in life, it is what you do with what happen to you". This is what I often use to encourage my patients.

– Dr. Obese

Is there a cure for Parkinson's?

There is currently no cure for Parkinson's disease but scientists are actively working to find disease-modifying therapies and a cure. Until then, there are different treatment options available to manage Parkinson's symptoms.



Do I have to take drugs for Parkinson's?

At some point, yes, you most likely will. Being diagnosed with Parkinson's, however, does not mean you will need to start taking drugs immediately. In the early stages of the diagnosis, some people are able to manage their symptoms without drugs, but this is not the case for everyone. The decision on when to start treatment, and what treatment options to use is a personal decision that you should make after weighing your options with your neurologist. Once you start taking drugs, you should continue taking them consistently, even after your symptoms improve. **You should not start or stop taking any Parkinson's drugs without discussing with your doctor.**

How can I best manage Parkinson's?

The best approach to managing Parkinson's involves a combination of drugs, therapies and healthy lifestyle habits – which involves exercising regularly, eating a healthy, balanced diet, ensuring that there is adequate good quality sleep and minimising exposure to stress. Some symptoms, however, will benefit from targeted treatment or therapies, for example, speech and language therapy for speech or swallowing difficulties, and physiotherapy for rigid muscles, balance and fear of falling.



OAUTHC Parkinson's Support Group, Ile-Ife, Nigeria

Are there any side effects to the drugs?

As with all drugs, Parkinson's drugs can have side effects. Some of these side effects need to be monitored closely as they can have a significant impact on daily living. If you are worried about these side effects, speak to your doctor. **Do not suddenly stop taking your drugs as you may experience serious and unpleasant withdrawal symptoms.**



Listed next are side effects of some Parkinson's drugs. Having a good understanding of them puts you in a better position to make informed decisions if you start to experience them.

Side effects of Parkinson's drugs

Dyskinesia:

Uncontrollable muscle movements that look like jerks or writhing movements. They can affect various parts of the body such as the arms and legs. It happens after prolonged use of levodopa (a Parkinson's drug).

Motor fluctuations and wearing off:

These occur when you go from having good control of your movement symptoms (being "on") to having less control (being "off"). They usually happen when the effects of levodopa start wearing off.

Impulse Control Disorders:

These happen when a person has an overwhelming urge to behave in a certain way. They will often carry out their behaviour repetitively as a way to reduce the worry or tension they get from their urge.

Hallucinations and delusions:

Hallucinations are seeing, hearing or feeling things that aren't there. Delusions are unusual thoughts, beliefs or worries that aren't based on reality. Not everyone will experience this side effect and it is more common in the later stages of Parkinson's.

Sleep disorders:

Some Parkinson's drugs can make you very sleepy without warning. Read the drug labels carefully.

Blood pressure changes:

Some Parkinson's drugs can make your blood pressure fall quickly, causing you to feel dizzy or faint. It is advisable to monitor your blood pressure regularly.

What should I eat?

While there are ongoing studies looking at the effects of diet on Parkinson's symptoms and Parkinson's medication, there is no one therapeutic diet that is broadly accepted as the 'right way' to eat with Parkinson's disease. What is universally accepted and recommended is that getting proper nutrition from a healthy diet is essential to your wellbeing.

Generally, the rules for following a healthy diet are to:

- Eat different types of foods from each of the different food groups (carbohydrates, proteins, vitamins, and so on) to ensure that your body is getting the nutrients it needs to function properly.
- Be mindful of your portions sizes. Overeating can lead to weight gain and not eating enough can lead to weight loss; both of which will add further health complications.
- Drink water to stay hydrated.



Can I take food supplements?

Ideally, you should get your nutrients from food rather than supplements. If you feel the need to take supplements, you should ask your neurologist or dietitian for advice before taking them. It is important to note that there are numerous claims about the ability of different supplements to improve Parkinson's symptoms; aside from the fact that many of these claims have little to no supporting scientific evidence, you should also be aware that some supplements could interfere with the absorption of your drugs.



How does food affect my drugs?

For some people with Parkinson's, proteins (which can be found in meat, fish, eggs, cheese and beans) seem to interfere with how well levodopa (a Parkinson's drug) is absorbed by the body. Because of this, you may benefit from taking your medication 30 - 60 minutes before you eat a meal, or two hours after. Levodopa can also make people feel sick. Eating a low protein snack (like biscuits) when you take your dose may help to reduce this side effect.

What role does exercise play in Parkinson's?

As with proper nutrition, exercise is an essential part of well-being for everyone. In Parkinson's disease, however, exercise is especially important. Sometimes, motor symptoms (such as stiffness) and non-motor symptoms (such as apathy, pain or fatigue) can discourage you from even trying to exercise; however, it is really important you understand that when it comes to managing your symptoms, exercise is just as important as medication and can help improve sleep, improve constipation or problems with mood, and reduce discomfort from pain and other symptoms affecting mobility. Studies show that doing 2.5 hours of exercise a week can improve your symptoms and slow down your progression. Also, regular exercise helps you cope with some of the side effects of your medication.



Chair-Based Exercise Class
Parkinson's Support, Constantia Park, South Africa

What type of exercise should I be doing?

There is no ideal exercise for everyone. You should focus on activities that you enjoy and are physically able to do. There are so many different activities you can do to stay physically active. Depending on your symptoms and physical abilities, you can do exercises that requires some effort like brisk walking, cycling, swimming, running, shadowboxing, dancing, trekking, push-ups, skipping, or even weight lifting.



OAUTHC Parkinson's Support Group, Ile-Ife, Nigeria

If you've had Parkinson's a long time, or your symptoms are more complex, you could focus on improving activities you have difficulty with like getting up from a chair, twisting, gardening, general body stretches, heel-to-toe walking, and arm swinging. If you have trouble standing or maintaining your balance, you can do some of these activities seated.

As the disease progresses, you can expect to make gradual changes to your daily life as you may need more help doing things. There are lots of aids you can use to make life easier. It can be difficult to accept the need to start using aids, but you may find that specialised equipment (for example grab rails or walking sticks) can actually help you become more independent. There are all kinds of aids and equipment available to help you if you have problems performing activities such as washing, bathing, reaching, eating and drinking.

Many people with Parkinson's are able to maintain a positive attitude in spite of their challenges. They do this, not by pretending that nothing is wrong, but by understanding how Parkinson's affects them, and then working around it. Part of this process involves doing the things that bring peace and joy (for example, listening to music, taking a walk, dancing, volunteering for a good cause, meditation, and so on). Also helpful is focussing on the things you can do rather than the things you cannot do.



**Wasswa Mohammed, Uganda
(Person living with Parkinson's)**

Can I still drive with Parkinson's?

A Parkinson's diagnosis does not necessarily mean you have to stop driving; however, your neurologist is in the best position to make this assessment with you. Please note that drowsiness and sudden onset of sleep are side effects of some Parkinson's drugs, and this can sometimes be severe. If you experience any of these symptoms, **you should not drive** and you should inform your neurologist as soon as possible.



Can I continue working with Parkinson's?

Yes! Just because you've been diagnosed with Parkinson's doesn't mean you have to stop work. Work is an important source of income, and can also build confidence and self-esteem. You should carefully consider talking to your employer about your condition because your symptoms will eventually become obvious.

What is my role as a care partner?

Your role as care partner will involve wearing multiple hats such as being a healthcare advocate, managing and scheduling medications, assisting with daily care, (like maintaining hygiene and getting dressed), and providing emotional support for the person you care for. This role will change as time goes on. As the disease progresses, people with Parkinson's will need more assistance with everyday activities. Having a good understanding of the disease and its symptoms equips a care partner to best care for the person with Parkinson's.



**Betty and Mike Anderson, Kenya
(Couple affected by Parkinson's)**

What about my needs?

One of the biggest challenges caregivers face is balancing their own needs against that of the person they are caring for. Making out time for yourself away from caregiving duties, maintaining other social connections, and asking for help when needed are important to help you cope with your additional responsibilities and stress.

*If you want to go fast, go alone.
If you want to go far, go together.
- African proverb*

We are on a mission to fully empower the African Parkinson's disease community, but we cannot do it alone – we need you! Whether you have been diagnosed with Parkinson's disease, or you know someone (a friend, coworker, neighbour, relative, etc.) whose life has been impacted by Parkinson's, or you are a health professional who sees people living with Parkinson's, you are an important part of our community.



**Parkinson's Awareness Walk
Parkinson's Si Buko Support Group, Uganda**

We want to go far – far in addressing the lack of Parkinson's awareness across the continent of Africa, and in reducing its associated stigma; far in increasing our community's engagement and representation in Parkinson's research; and far in improving access to Parkinson's healthcare and treatment options for those who lack it.

We know we can't go far by ourselves, so we are asking you to join us as we build and expand this community. Please visit **www.parkinsonsafrica.org** for more information on how to join us.



**Parkinson's Awareness Walk
Parkinson's Si Buko Support Group, Uganda**

Please contact teamafrika@parkinsonsafrica.org if you know of a Parkinson's support group in Africa that is not listed below.

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Translated versions of this booklet (in other African languages) are also available. Please visit **www.parkinsonsafrica.org** or **www.ipdgc-africa.com** for more information.



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