

## Newly diagnosed with Parkinson's disease

If you've just been diagnosed with Parkinson's disease, it can feel like a huge shock. It may trigger a range of emotions including confusion, sadness, anger, and fear. You may have lots of questions about the condition and the impact it's going to have on your life, relationships, and work. You may also be concerned about telling your friends, family, and employer about your diagnosis. Read on for advice about coping with a diagnosis of Parkinson's disease and how to move forwards as you process having the condition.

#### **Table of Content**

Understanding your diagnosis	1
What if it's hard to come to terms with your Parkinson's diagnosis How to tell family and friends about having Parkinson's disease	

### Understanding your diagnosis

Being diagnosed with Parkinson's is a very different experience for everyone. Some people may go through a combination of shock, denial, anger, confusion, and fear; while others may experience some sense of relief at finally getting to the root cause of the different symptoms they have been dealing with.



A Parkinson's diagnosis may cause you and your loved ones to worry about how the disease will affect your lives, and about what the future will look like as your symptoms progress. You may be concerned about being stigmatised due to the general lack of awareness and understanding of Parkinson's disease across Africa. Cultural norms and religious beliefs may also contribute to these concerns, and you may struggle with coming to terms with the diagnosis.

Whatever your initial reaction is to the diagnosis, your feelings are your feelings, and it is important to be aware that there is no 'normal' way to feel or to process all your emotions. Equally important to note is the fact that the emotions surrounding your diagnosis may very well change from day to day.

Remember that your diagnosis is not your fault. And although there is no cure for Parkinson's, with some lifestyle changes and treatment, you can control your symptoms and have a good quality of life. There are <u>ways you can live</u> <u>well with Parkinson's</u> and slow down its progression.

It's also important to know that you are not alone. Getting support and talking to friends, family members or other people with Parkinson's can help you process your diagnosis.

# What if it's hard to come to terms with your Parkinson's diagnosis

Coming to terms with your condition is a process that will be very personal to you.

It is not uncommon for people to feel depressed and anxious about the future, or even try to block out the diagnosis and deny that it's happened. It is also not



uncommon for some people to feel inspired to get the most out of life and make changes that can help them live well with the condition.

You may go through several stages as you come to terms with the diagnosis. So, give yourself time and space to process whatever emotions you are experiencing.

Below are some things you could do to help process the diagnosis:

- \* Write down or speak to a loved one, a trusted counsellor, or a trained health care provider (if available) about how you are feeling.
- ★ Learn more about what <u>support is available</u> to help you and speak to other people in your situation to gather their wisdom.
- ★ Focus on the things you can do rather than the things you can't. Boost your mental and physical health with a <u>healthy diet</u> and <u>regular exercise</u>, if and when you feel motivated.
- ★ And think back to other barriers and challenges you've overcome in your life and draw on these experiences for comfort.

## How to tell family and friends about having Parkinson's disease

In making the decision of whether or when to tell people about your diagnosis, it is important to remember that Parkinson's is a progressive illness (which means that it gets worse over time). As a result, whether or not you choose to tell people about the diagnosis, your symptoms will become more obvious and difficult to hide at some point. This does not mean that you need to disclose your diagnosis immediately, but it's something you should be aware of.

In disclosing your diagnosis to loved ones, you must carefully consider who you are telling, how the news of your diagnosis will impact them, and how their reaction to your diagnosis will impact you. People may be upset, just as you



were, and that can feel like a burden you have to take on. You may have to account for managing the resulting worry and concern from telling an elderly parent, for example.

Some people find that speaking to other people helps them come to terms with the diagnosis and deal with the emotional stress, but taking the leap and telling those around you can also be a source of worry, particularly if people don't understand the disease and believe in some of the myths associated with it.

When you do decide to tell people about your diagnosis, here are some helpful tips:

- \* Stagger when you tell people your news. You don't have to inform everyone at the same time. Perhaps you tell those very close to you and wait to tell other people.
- ★ Think ahead, choose a quiet, relaxed time and plan what you'll say. Tell your loved ones about the disease, your symptoms, any treatment options and what you can do to control your symptoms.
- ★ If you're speaking to children, how much detail you use will depend on their age. But clear, simple language and staying calm will help whatever their age. There are child-friendly resources available online to help you with these conversations.
- ★ Encourage your loved ones to read <u>health information resources</u> from trusted sources, if they have any questions. You could even make a list of questions together that you could ask your doctor or research for yourselves.



## Getting help and support if you're newly diagnosed with Parkinson's

There are lots of <u>myths and misconceptions</u> about Parkinson's. So, it's really important to get your advice from trustworthy sources, like Parkinson's Africa. Make sure you read through our articles to get clued up on everything from everyday living advice to what happens during the different stages of Parkinson's.

Your options for face-to-face support will depend on where you live and what healthcare resources are available there.

You may also have to rely entirely on a general doctor for your Parkinson's care. But you may be able to access a neurologist or a movement disorder specialist and other healthcare professionals for therapies such as physiotherapy and occupational therapy.

Whatever the situation, creating a support network of friends, family or community members around you is vital. They can help you share the emotional load and support you physically too.

### Sources (all accessed June 2022):

- Christensen JH. nd a. I've got Parkinson's. Now what? Parkinson's Foundation. <a href="https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/lve-Got-Parkinsons-Now-What">https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/Ive-Got-Parkinsons-Now-What</a>
- Christensen JH. nd b. Telling family about the diagnosis. Parkinson's Foundation.
  <a href="https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/Telling-Family-About-the-Diagnosia">https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/Telling-Family-About-the-Diagnosia</a>
- Hamel SS. 2021. Patient perspective: Parkinson disease.
  <a href="https://www.uptodate.com/contents/patient-perspective-parkinson-disease">https://www.uptodate.com/contents/patient-perspective-parkinson-disease</a>



- JHM. Nd. Newly diagnosed with Parkinson's disease: 7 things to do now. <a href="https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/newly-diagnosed-with-parkinsons-disease-7-things-to-do-now">https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/newly-diagnosed-with-parkinsons-disease-7-things-to-do-now</a>
- NHS. 2019. Living with Parkinson's Disease. <a href="https://www.nhs.uk/conditions/parkinsons-disease/living-with/">https://www.nhs.uk/conditions/parkinsons-disease/living-with/</a>
- Parkinson's UK. nd. Newly diagnosed with Parkinson's Disease. https://www.parkinsons.org.uk/information-and-support/newly-diagnosed-parkinsons

#### **Disclaimer**

This article 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 article as an alternative to medical advice from their doctors or other professional healthcare providers. Parkinson's Africa disclaims any responsibility and liability of any kind in connection with the reader's use of the information.