

Living with Parkinson's disease

While your experience of living with Parkinson's disease is unique to you, there are some general steps that you can take to live well and feel more in control of your life. We will explore the different ways in which you can continue to enjoy a good quality of life after your Parkinson's diagnosis.

If you've <u>recently been diagnosed</u> with Parkinson's disease, you may be experiencing a number of different emotions and you may be worried about what your future will look like. This can feel very overwhelming.

As you work through your emotions, you may find it helpful to remember that:

- ★ Parkinson's is life-altering, but it is not life-threatening in and of itself.
- ★ While there is no cure for Parkinson's, its symptoms can be controlled.
- ★ Help and support are available you are not alone.

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Daily life with Parkinson's disease

Parkinson's affects everyone differently, but it usually progresses slowly. This means that, generally speaking, it could take a number of years before a person's symptoms start to significantly impact their life.

As the disease and symptoms progress, you may start to have difficulties doing things that used to be easy. When this happens, you will find that there may be support, equipment and medication that can help you regain some independence. Always speak to a healthcare professional about what options and additional therapies are available to you. Therapies like occupational therapy and physiotherapy could be particularly useful as they can help you with mobility issues and improve your ability to perform everyday activities that have become more challenging.

If you don't have access to any of these resources, Parkinson's Africa may be able to assist. Please go to our <u>Support page</u> to see the local support services we have listed. If your locality is not listed, please <u>contact us</u> for further assistance.



Working

Working, and the financial benefits it provides, is an important aspect of most people's lives, and the fact that you have been diagnosed with Parkinson's disease does not mean you have to stop working. In addition to its financial benefits, earning an income could also be great for your sense of self-worth and independence.

If you do decide to continue working, you should carefully consider whether (and, if so, when) to inform your employer about your diagnosis. In making this decision, it is important to remember that as your disease progresses, your symptoms will become more apparent to your coworkers, and you may need specialist equipment or adjustments to help you continue to work.

Naturally, you may be concerned about telling people in your workplace about your diagnosis. Some people choose to keep their diagnosis a secret because they worry about how their coworkers would react and regard them as their diagnosis progresses.

Discussing your diagnosis early on can help you take back some control of that narrative. It can also help your boss and coworkers better understand that your symptoms are part of a physical disease and, additionally, clear up some of the myths surrounding Parkinson's.

Of course, depending on the severity of symptoms, not everybody with Parkinson's can or should work. At some point in your diagnosis, you may have to make the hard decision to give up your job early when working becomes too difficult. If your job requires driving machinery, for example, there may be a health and safety risk if you don't open up about your diagnosis and the impact of your Parkinson's medications on you. Another example: if your job requires steady hands, like carpentry, it may no longer be feasible for you to carry on in that line of employment if you have prominent hand tremors. Check out our <u>Support page</u> for details of organisations that may be able to provide advice.



Driving

Driving can also provide you with a sense of independence – and being diagnosed with Parkinson's doesn't necessarily mean you have to give up your licence or stop driving. However, you must always check with the driving authority in your country. You may be asked to have a regular medical examination or assessment to make sure you are safe and able to drive.

If you do continue to drive after your Parkinson's diagnosis, you need to be honest with yourself about your health and the possible risk you pose to yourself and other people. It can be hard to admit it's no longer safe to continue driving, but if, for example, your Parkinson's medication is causing sleepiness or your symptoms are affecting your reaction times and vision, you definitely should not drive.

Washing and dressing

During the early stages of Parkinson's disease when your symptoms are likely to be mild, you should be able to take care of yourself. But over time, your daily routine may become more challenging, and it may take you longer to complete otherwise simple tasks such as buttoning up a shirt or putting on your shoes.

Small changes, however, can make a big difference. For example, you could try to do some simple stretches everyday (especially before you get dressed) to enhance your flexibility and mobility. You should also be aware of the types of clothes you choose to wear - clothes and shoes with simple fastenings, such as zips are generally easier to put on than those with buttons or complicated laces. Handrails, special seats and non-skid rubber mats can make showers and baths safer. Using pump bottles for products and an electric toothbrush or



razor can help if your symptoms are getting in the way of your grooming routine.

Home life

There are lots of ways you can adapt your home to make it easier to get around and safer for you, which is particularly important in the later stages of Parkinson's.

For example, it's a good idea to make rooms less cluttered. Remove any obstacles, carpets or rugs in the house that could make you trip and fall. There are specially designed cooking and eating items that can help make mealtimes easier. Installing handrails can help you with walking. Making sure your bedroom is cool and dark can help with sleep problems. And choosing chairs or sofas that are firm and have secure armrests, makes sitting up straight more comfortably and can help you get up more easily.

Sharing everyday tips like these with other people who have Parkinson's is a great idea and can help you feel less lonely. We recommend joining a <u>local</u> or <u>virtual support group</u> to keep you connected with other people also living with Parkinson's - many people find this social aspect very beneficial.

Travelling

You can still travel when you have Parkinson's disease – you may just need to plan more in advance.

For example, if you're travelling overseas for an extended period, you may need a medical certificate from your doctor. Think about whether you need extra medication to use while you're away. If you are arranging travel insurance, make sure your policy covers pre-existing conditions and that you inform your



insurer. And whether you're going by air, rail or sea, let the company you're travelling with know if you need extra support.

Movement and exercise

Regular exercise is a great way to stay healthy and mobile. Research shows that 2.5 hours of active movement a week is enough to help ease some Parkinson's symptoms.

Regular physical activity can help improve your strength, balance and posture – and it's great for your mental wellbeing too.

The great thing about exercise is that there are so many types to choose from. So, whatever your fitness level and your symptoms, there will be one suited to you.

If you're not sure how to start exercising or what activities can help you, talk to your doctor or Parkinson's specialist.

For more information about exercising when you have Parkinson's, read our article about Exercising with Parkinson's disease.

Healthy eating

Eating a <u>healthy diet</u> is good for everyone, but it's particularly important if you're living with Parkinson's.

There is no specific eating plan you need to follow, the most important thing is to follow a balanced, varied diet. This will help you keep a healthy weight, keep your bones strong, help you to avoid constipation and maintain good health.



It can be really challenging to make changes to your daily diet, especially if you're not sure which foods are healthy, and which aren't. If you need help, speak to a healthcare professional, or a local <u>support group</u>.

You'll also find lots of useful information in our article on <u>Diet for Parkinson's</u> disease.

Relationships

Many people find that being open and honest with their loved ones helps them deal with their Parkinson's diagnosis. You may find that your closest relationships also become stronger.

But coming to terms with a Parkinson's disease diagnosis can be stressful if the people around you don't fully understand it. They may become frightened and anxious. They might not have the right facts about Parkinson's so they may think that <u>some common myths</u> are true. For example, they might believe your symptoms are the result of a curse or that your condition is contagious and that they are at risk.

Because of this, some people choose not to share their <u>Parkinson's diagnosis</u>. However, as your condition progresses, <u>symptoms such as tremors</u> will become impossible to hide. It's important to share information about Parkinson's with them, so they understand the condition.

For advice on telling friends and family, check out our <u>Newly diagnosed with</u> Parkinson's article.



Sex

Parkinson's can lead to movement problems, tiredness, incontinence and depression, all of which can affect your sex life. Unfortunately, you may also find it more difficult to feel aroused, which may make you feel less desirable.

Some people taking a type of medication known as dopamine agonists may also experience hypersexuality, which leads to intense sexual impulses.

Don't be embarrassed to speak to a doctor or Parkinson's specialist if you can about any sexual problems you are experiencing. They will be understanding and will try to find ways to help you.

Be honest with your partner about how your Parkinson's is affecting you – they may not be fully aware and may be feeling nervous too.

Mental health

It's common to experience mental health issues such as stress, anxiety, and depression when you're living with Parkinson's. These may be caused directly by the way Parkinson's physically affects the brain and indirectly by the emotional upheaval of your diagnosis.

Memory problems and difficulties with thinking are also common with Parkinson's disease. You may take longer to make decisions or respond to people asking you questions. It can also affect your ability to concentrate and focus your attention.

Your mental health is just as important as your physical health. Speak to your doctor or specialist if you're struggling. Chatting with others living with Parkinson's can also help.



For more information on the mental health effects and symptoms of Parkinson's disease read our article on Parkinson's and mental health.

Sources (all accessed June 2022):

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