

Understanding Parkinson's: A Guide to Support and Advocacy



Parkinson's disease is a progressive neurological disorder that affects movement, causing symptoms that worsen over time. It is characterised by tremors, stiffness, and difficulty with balance and coordination.



Despite being one of the most common neurological disorders affecting older adults, Parkinson's disease can be difficult to understand and manage, both for those diagnosed and their loved ones. This guide aims to provide insight into the nature of Parkinson's disease, offering support and advocacy advice to navigate this challenging condition.

Understanding Parkinson's Disease

Parkinson's disease is caused by the degeneration of nerve cells in the part of the brain called the substantia nigra, which controls movement. These nerve cells produce dopamine, a chemical that sends messages to the part of the brain that controls movement and coordination. As Parkinson's disease progresses, the amount of dopamine produced in the brain decreases, leaving a person unable to control movement normally.

The exact cause of this degeneration is unknown, although it is believed to be a combination of genetic and environmental factors. Symptoms of Parkinson's disease develop slowly and are often subtle at first. The most common symptoms include tremors or shaking, slowness of movement (bradykinesia), stiffness or rigidity of the limbs and trunk, and postural instability (balance problems). Other non-motor symptoms can include sleep disturbances, mood changes, cognitive impairment, and autonomic dysfunction.

Diagnosis

Diagnosing Parkinson's disease can be challenging, as there is no definitive test for the condition. Instead, neurologists rely on medical history, symptoms, and physical and neurological examinations to make a diagnosis.

In some cases, imaging tests such as MRI or DaTscan may be used to rule out other conditions that could cause similar symptoms. It's important for those experiencing symptoms to seek a specialist in movement disorders, as they can provide a more accurate diagnosis and tailored treatment plan.

Treatment and management strategies

There is currently no cure for Parkinson's disease, but a variety of treatments are available to help manage the symptoms and improve quality of life.

Treatment plans are highly individualised, as the effectiveness of different therapies can vary from person to person.

Medication

The most common approach to managing Parkinson's disease is through medication. The aim is to increase dopamine levels in the brain or to mimic the action of dopamine. Levodopa, combined with carbidopa, is the most widely used treatment. Levodopa is converted to dopamine in the brain, while carbidopa prevents it from being broken down before it reaches the brain.

Other medications include dopamine agonists, which mimic dopamine effects; MAO-B inhibitors, which help prevent the breakdown of dopamine; and others that may be used to manage specific symptoms such as tremors or rigidity.

Surgical treatments

For some people with Parkinson's disease, surgical options may be considered when medications are not effective. The most common procedure is deep brain stimulation (DBS), where electrodes are implanted in specific areas of the brain. These electrodes are connected to a generator implanted in the chest that sends electrical pulses to the brain, which can help reduce symptoms.

Physiotherapy and exercise

Regular physical activity and physiotherapy are crucial in managing Parkinson's disease. Exercises can improve flexibility, strength, and balance, helping to reduce the risk of falls and improving overall mobility. Tailored exercise programs can be developed to meet the individual needs of those with Parkinson's disease.

Occupational therapy

Occupational therapy can help individuals with Parkinson's disease maintain their independence by assisting them in adapting their living environment to their mobility needs. This may include recommending changes to the home to make daily activities easier and safer, as well as teaching strategies to manage tasks related to personal care, work, and leisure activities.

Supportive therapies

Speech and language therapy can help with communication difficulties, while nutritional advice can help manage weight and ensure a balanced diet. Psychological support, including counselling or therapy, can also be beneficial in coping with the emotional aspects of living with a chronic condition.

For those navigating this condition, remember that you are not alone.

Finding support

Support groups can be invaluable for people with Parkinson's disease and their families. These groups provide a space to share experiences, advice, and encouragement. They can also be a source of information about living with the condition, coping strategies, and updates on research and treatments. Many charities and organisations dedicated to Parkinson's disease offer local support groups, online forums, and helplines.

Advocacy

Advocacy is crucial in ensuring that those with Parkinson's disease receive the care, support, and resources they need. This can involve advocating for oneself in healthcare settings, such as asking for referrals to specialists, seeking out second opinions, or discussing treatment options and preferences with healthcare providers.

Family members and caregivers can also play a key role in advocacy, helping to navigate healthcare systems, access services, and apply for benefits or financial assistance. It's important for caregivers to also seek support for themselves, as caring for someone with a chronic condition can be physically and emotionally demanding.

Raising awareness

Raising awareness about Parkinson's disease is vital in increasing understanding, reducing stigma, and promoting research into new treatments and a cure. Participating in awareness campaigns, fundraising events, and community education can help bring attention to the condition and the needs of those affected by it.

Engaging with research

Participation in clinical trials and research studies is another way people with Parkinson's disease can contribute to the advancement of knowledge and treatments. Engaging with research not only offers the potential to access new therapies but also helps scientists and doctors better understand the disease and its impact on individuals and families.

While the journey with Parkinson's can be complex and challenging, with the right treatment, support, and resources, individuals with Parkinson's disease can lead active and meaningful lives. It's important to focus on what's achievable, seek out community and support, and engage actively in managing the condition. By advocating for comprehensive care and supporting research, we can all contribute to a future where Parkinson's disease can be effectively treated and ultimately cured.

This article incorporates content reproduced with the kind permission of HealthHero.

About WPA

WPA is a specialist not-for-profit health insurer. With a history dating back to 1901 they look after private individuals, families and all businesses from micro enterprises through to blue chip global brands.