

Newly Diagnosed Parkinson's Disease FAQ's

What is Parkinson's Disease?

Parkinson's Disease (PD) is a progressive neurological disorder. It is predominantly characterised by motor symptoms but the non-motor and neuropsychiatric symptoms are becoming increasingly recognised by experts. As part of the normal aging process dopamine levels decrease but a person with Parkinson's disease experiences loss of dopamine at a faster rate. PD is the loss of a neurochemical called Dopamine. Dopamine is responsible for smooth/controlled movement, mood, cognition & motivation, amongst other things. The cause of PD remains unknown (idiopathic) although there are some indications that genetics and environmental factors may play a role in some diagnosis.

What is the prognosis and progression with Parkinson's Disease?

Parkinson's Disease is usually diagnosed when approximately 80% dopamine has depleted. The symptoms experienced, treatment and progression of the disease is individual to each person. Therefore a tailored approach is important "Seven million people, seven million variants of Parkinson's," Bas Bloem 2021

Is there a cure for Parkinson's Disease?

Unfortunately, there is no cure for PD. Research is ongoing on a global level. There are new treatments being brought to our attention frequently, but a cure is yet to be found. Medications can assist in the control and management of symptoms. A holistic approach can empower a person alongside pharmacological treatment. Always speak with your physician if considering a complimentary therapy. Exercise, at a level of intensity suitable to the individual, has been shown in multiple research papers to slow the progression of PD.

How do I optimise medication?

Medication regimes will vary from one person to another. The prescription of medications will be dependent on the treatment regime a consultant will follow, your symptoms experienced and their impact also. If commencing a medication, a physician may introduce one at a time to eliminate potential side

effects and monitor effectiveness. Introduction of new medications or dose changes may take up to seven days before benefit is seen.

Never stop any Parkinson's medications without consulting with the prescribing physician. If you are experiencing any side effects or unsure if medications are ****effective** speak with your physician.

Optimising levodopa medication. Levodopa is absorbed in the bowel, some people will find protein & high fat intake can affect its absorption, therefore it is suggested:

1. Take levodopa medication 30 minutes before food or 60-90 minutes after food.
2. Take with full glass of water (minimum 200mls).
3. Ensure regular bowel motions. If constipation is an issue initiate dietary fibre changes or speak with your physician.
4. Be consistent in timing of medication- set reminders if necessary.

Does everyone with Parkinson's disease experience a shake/tremor?

No, not everyone with PD will experience a tremor. Parkinson's disease can cause motor symptoms (tremor, slowness, stiffness etc) and non-motor symptoms (bowel, bladder, sleep, speech, cognition, anxiety etc).

Does Parkinson's disease affect cognition?

Mild cognitive issues may be experienced by approximately 25%- 50% of those living with PD. Mild cognitive issues may include: difficulty concentrating, difficulty multitasking, language difficulties & altered visuospatial skills. Mild cognitive changes occur as part of the normal aging process. Cognitive impairment is a change in thinking or memory that is more than expected with normal aging but is not enough to interfere with a person's daily activities.

Can I be involved in research?

Yes you can, studies are ongoing in multiple centres. Please speak to your neurologist or PD nurse specialist if this is something you would like to participate in.

Does diet play an important role?

Diet can play an important role in improving some of the symptoms people with PD may experience such as: Unintentional weight loss or gain, chewing and swallowing difficulties, constipation and dehydration. A Dietitian can help you to manage dietary issues related to your PD and advise on the best diet to maximise the effect of your PD medications. Please see 'Eating Well with Parkinson's Disease' booklet for further information.

Is Parkinson's Disease inherited? Should my family get genetic screening?

Approximately 15% of those with PD have a genetic link. It is very rare for Parkinson's to be genetic. There are certain gene variants that have been identified that are linked to Parkinson's disease. Researchers have identified specific genetic mutations that are linked to increase the risk of developing young-onset PD. While genetic testing is available, not everyone who has these genetic mutations develops PD, and the presence of these genetic mutations does not impact treatment decisions.

Can I Still Drive?

Yes, you can continue to drive, unless you feel your reactions may be delayed or have safety concerns. When diagnosed with PD you are required to notify the National Driving Licence Service (NDLS). A medical report form may be required & can be completed by your physician.

How will this diagnosis affect employment?

Your Parkinson's may have no impact on your ability to perform your role within employment. A diagnosis of Parkinson's disease does not necessarily mean you have to stop work and most of the time people with

PD are able to continue their employment and carer for many years. You may be required to notify your employer if your condition may have an impact on health & safety in the workplace. It is recommended you make your employer aware of diagnosis as they may be able to assist. It is an individual decision as to whether you notify your employer.

What financial help or benefits are available to me?

Information regarding benefits which may be available to you and your family can be obtained from the Citizen's Information website or your local Citizen's Information Centre.

Long Term Illness Scheme- Parkinsonism is one of the medical conditions that qualifies for Long Term Illness Scheme. Under the Long-Term Illness (LTI) Scheme you can get some drugs, medicines for free from your pharmacy. There is no means test for the scheme. You do not have to pay a prescription charge for the drugs you are approved for under the Long-Term Illness Scheme. Other drugs and medicines not related to the specified condition must be paid for. See www.hse.ie for further information or contact your local health office.

What can Parkinson's Association of Ireland (PAI) offer me?

PAI membership offers you a connection with like-minded people experiencing a similar situation. There are branches located nationwide including YPI (Young Parkinson's Ireland). PAI offer support & education to those living with PD or caring for those with PD. PAI provide a nurse support line, dietician call back service and multiple branch & online activities. You also receive quarterly magazines & weekly newsletters to keep you up to date with any research, events or general information on Parkinson's Disease.

Further information:

www.parkinsons.ie	www.welfare.ie
www.parkinsons.or.uk	www.hse.ie
www.parkinson.org	www.epda.eu.com

Bastian R. Bloem, Michael S. Okun, Christine Klein. Parkinson's disease. The Lancet. DOI: 10.1016/S0140-6736(21)00218-X