

Useful information about Parkinson's

Information for patients

Parkinson's is a lifelong progressive brain disorder where there is premature loss of nerve cells in the brain, in particular, dopamine secreting nerve cells. This leads to a variety of motor (such as movement and balance) and non-motor symptoms. Unfortunately, we do not currently have medications that can slow down or halt the progression of Parkinson's. There are a number of treatments that may help relieve the symptoms.

In normal circumstances, Parkinson's symptoms do not change dramatically. If there is a sudden change, then there is usually an underlying cause, such as infection or constipation, for example. In these circumstances, you should contact your GP for appropriate treatment. In cases of emergency, use the appropriate services (call 999 or 111) .

If you are unwell with other health related issues, such as infection, you will notice your Parkinson's symptoms may be more enhanced. You will get better, but your recovery may take longer than expected.

For advice relating to your Parkinson's that you feel cannot wait until your next scheduled appointment, you can contact the Parkinson's nurses. Telephone clinics are held on Monday, Wednesday, Thursday and Friday mornings.

To book a telephone consultation call 0131 465 9156
Monday to Friday 08.30am – 10.30am.

Your call will be answered by one of our secretaries who will give you a date and time when one of the nurses will call you back. If you hear a recorded message between these hours, please hang up and call back as our lines are busy. Please do NOT leave a message as this will not be responded to.

Medication

Parkinson's medication helps boost dopamine levels when the brain is not making enough of its own. Around 80% of dopamine producing cells will have died by the time symptoms are obvious.

Levodopa is the most commonly used medication to treat Parkinson's symptoms. This medication has been in use since the 1960's, is effective in easing symptoms and is usually well tolerated. There are a range of other drugs which may be used alongside Levodopa, but treatment is tailored to the individual and so not everyone with Parkinson's will be prescribed the same medications.

Medication is introduced at a small dose and slowly increased according to response. The aim is to keep the medication dose as low as possible but to enable a person to have reasonable function.

The Parkinson's tremor may not always respond well to medication, but people will often see an easing of muscle stiffness and rigidity.

Parkinson's medication is usually well tolerated; however, it should initially be taken with food to help avoid side effects such as nausea or dizziness. After a couple of weeks, this medication works better on an empty stomach and so is better taken either 30 minutes before food or at least 1 hour after meals. Protein may affect the absorption of Parkinson's medication and by keeping a gap between medication

and food, this will help avoid absorption issues. We would not suggest eliminating protein from your diet. Parkinson's medication works best if you try to take it at the same time every day.

You may read that after taking Parkinson's medication for some years, people develop involuntary movements known as dyskinesia. By keeping the dose level low, the aim is to try to avoid this symptom. People should not be nervous about using Parkinson's medication for this reason.

Websites may also state that medication stops working after 5 years. This is not correct however; medication doses may require adjustments to help manage the symptoms.

There are some drugs that block dopamine pathways in the brain and so should be avoided in people with Parkinson's. Anti-nausea drugs such as Metoclopramide and Stemetil are commonly prescribed but should not be taken by someone with Parkinson's. Some antihistamines and cold remedies are also not advisable.

Make sure you mention that you have Parkinson's to anyone who is prescribing you medication.

Your local pharmacist is a good source of information about all medication. If you are not sure what medication you can take with Parkinson's, then please ask them.

Your GP practice should have an allocated Clinical Pharmacist who oversees medication prescribing. They may cover different practices but should be available for you to discuss medication concerns. If you are having issues with your prescription you can ask to speak to them when they are next on site.

Impulse Control Disorder (ICD)

You may read about impulsive or compulsive behaviours that occur by taking Parkinson's medications. There is a very small risk of this happening and is mostly linked to a certain kind of medication, namely dopamine agonists. However, these side effects can occur with any Parkinson's medications.

The side effects that some patients may experience are increased sex drive, gambling or compulsive shopping. Some people may also note an increase in hobbies, binge eating or generally an inability to switch off and relax. We will ask you about these symptoms at your clinic visits. If you develop any unusual symptoms, then please inform your Parkinson's consultant or nurse as a reduction in the dose of your medication or a change to another drug will help settle the problem.

Lifestyle and future planning

As well as medication, the importance of a healthy lifestyle cannot be underestimated with Parkinson's. Following a healthy diet with good fluid intake, having a good sleep pattern, and incorporating exercise into your daily routine is extremely beneficial. Information about exercise can be found through video links on the Parkinson's UK website and local information can be found on the Edinburgh branch website (links and QR codes overleaf).

Regardless of age, it is important that we all plan for our futures. This is relevant to all of us and not just to those who have Parkinson's.

It is important that while we are able, we make arrangements and put in place a Will and Power of Attorney (POA). This means that, should we lose capacity to make decisions, we have documented our wishes and named a person to speak on our behalf (POA). Visit the website below or scan the QR code using the camera on your phone for more information:

www.mygov.scot/power-of-attorney/further-information



Driving

You are required by law to inform the DVLA of your diagnosis. The DVLA will post you forms to complete every 3 years. Please add your Parkinson's consultant and GP as the people for the DVLA to contact and NOT the Parkinson's nurses. They will also be asked to complete a similar form about your current condition and ability to drive. You should also inform your car insurance company.

Having a diagnosis of Parkinson's does not mean you are no longer allowed to drive. However, you have a duty of care not to drive if you are not fit to do so. If a healthcare professional feels you are not safe to drive, it is your responsibility to heed this advice and inform the DVLA of a change in your condition.

Research

We have research teams based at the Western General Hospital and the Anne Rowling Clinic at Edinburgh Royal Infirmary. For those interested in taking part in research and clinical trials, you can sign up to our two local data bases.

Visit the Rowling Care website below to sign up to the Rowling registry. You will receive a permission to contact form for the Neuroprogressive and Dementia Research register which will let the research teams know you have given them permission to contact you to discuss any current potential studies. You can also find more information through the Edinburgh Parkinson's branch which has links to the Edinburgh Research Interest Group (ERIG).

www.rowling-care.org.uk



Peer support

You can find local peer support on the Edinburgh Branch of Parkinson's UK and all the activities on the internet. This covers the whole of Lothian and not just Edinburgh.

www.edinburghparkinsons.org



Please also read about the First Steps self-management online course:

www.edinburghparkinsons.org/activities-and-events/first-steps-programme/



Other useful websites for information about Parkinson's

Parkinson's UK www.parkinsons.org.uk	
The Cure Parkinson's Trust www.cureparkinsons.org.uk	
Michael J. Fox Foundation www.michaeljfox.org	
Davis Phinney www.davisphinneyfoundation.org	

