

# Have you recently received a diagnosis of Parkinson's disease?

## What's the next step?

**Information for patients**

This leaflet has been written to help people newly diagnosed with Parkinson's who are live in Oxfordshire and South Northamptonshire. It contains useful resources on:

- General information on common symptoms.
- General information on types of medication used to treat symptoms of Parkinson's.
- Other ways of helping your Parkinson's symptoms (such as exercise).
- Referral pathway to the Parkinson's Nurse Specialist and how your follow- up reviews will be arranged.

## **What is parkinson's?**

Parkinson's is a long-term progressive neurological condition that arises due to loss of dopamine producing nerve cells in the brain. Motor symptoms include, tremor, stiffness in muscles and slowness in movement. People can also experience other symptoms (non- motor symptoms) such as mood or sleep.

**It's important to remember that people experience Parkinson's in different ways and symptoms and treatment may be different to other people with Parkinson's.** Therefore, the Parkinson's team will support you individually, involving you in all aspects of your care, and involving you in all discussion around possible treatment options.

## Symptoms you may experience

You may experience the following MOTOR symptoms:

- Tremor (shaking or trembling).
- Stiffness (often referred to as rigidity).
- Slowness of movement (often referred to as bradykinesia).

Some other NON-MOTOR symptoms you may experience:

- Balance problems -you may be more at risk of falls.
- Changes with your bowels or bladder.
- Difficulties with sleep.
- Eating, swallow and saliva control.
- Speech and communication changes.
- Changes in mood (for example feeling anxious).

## Common descriptions used to describe symptoms

There are a few terminologies we use to describe common symptoms in Parkinson's. Some of the most common ones are:

**ON state** – this is when you feel at your best.

**OFF State** – this is when you feel your Parkinson's is at its worst.

**Dyskinesia** – involuntary movements and you cannot easily control.

**Freezing** – when you may suddenly feel your feet get 'glued to the ground' or can sometimes happen with speech.

**Wearing OFF** – your medication has less effect, and your symptoms worsen often before your next dose.

**Gait** – this is a manner of walking.

# Referral /review pathway

## 1. Initial referral

- Your GP or in some cases another health care professional will have referred you to either a Geriatrician or a Neurologist who has expertise in Parkinson's.

## 2. Appointment with the Hospital Specialist

- Your clinical diagnosis is made, and they may also discuss treatment options.
- You will be referred to the Parkinson's Nurse Specialist **close to where you live**. Details can be found in the leaflet 'Parkinsons Nurse Specialist Service' found inside your Information Pack.

## 3. First review with your Parkinson's Nurse Specialist

This is usually within the first 6 to 8 weeks of your diagnosis.

- Your Nurse will talk to you about your diagnosis and answer any questions you may have.
- They may refer you to the Multidisciplinary team.
- Talk to you about the PD UK First Steps Programme.

## 4. Follow up reviews

- You should have a follow up arranged with **your Specialist** at least once a year.
- You will be offered a local follow up with **your Parkinson's Nurse** routinely in between your specialist reviews, but this can be more frequent if needed. In some cases, a home visit may be offered.

## Common medications used to treat symptoms of parkinson's

You may be prescribed oral medication when you are first diagnosed such as;

- Co-beneldopa
- Co-careldopa
- Ropinirole
- Pramiprexole
- Rasagiline
- Selegiline

These are the generic names of the drugs but many also have brand names. If you are ever unsure about the name of your medication, please do speak to your Nurse, Specialist or your local Pharmacists.

You can also find very helpful information on drug treatments in Parkinson's on the Parkinsons UK website [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

## Medication management

Take your Parkinson's medication **on time** to help you manage your symptoms effectively.

**Never suddenly stop** your treatment, as this can cause side effects.

If you have difficulties taking your medication, please speak to your Parkinson's Nurse or Consultant as soon as possible.

If you need to go into hospital, always take you Parkinson's medication in with you, in the original, labelled containers as these are rarely stocked in the ward drug cupboards.

## Other advanced therapies

Your Specialist or Nurse may discuss other more advanced treatments available later into your diagnosis with your consultant. These are available at John Radcliffe Hospital, Oxford and include:

- **Deep Brain Stimulation** (DBS) – a surgical procedure
- **Apomorphine** (given by an injection or infusion)
- **Duodopa** – a levodopa intestinal gel that is delivered through a PEGJ tube into your small bowel.
- **Produodopa** – a levodopa intestinal gel delivered via subcutaneous injection was funded nationally by NHS England Feb 2024. It will be made available once we have the team and resources to support this.

## Activities in your local area

Regular physical activity is important and will improve your gait, your balance and your mood.

**Big, Bold and Balance classes** (for people with Parkinson's)

Phone Age UK Oxfordshire: 01235 849 403

Email: [active@ageukoxfordshire.org.uk](mailto:active@ageukoxfordshire.org.uk)

**A variety of physical activities through Oxfordshire Age UK**

(available online, or in local classes)

Phone Age UK Oxfordshire: 01235 849 403

Email: [active@ageukoxfordshire.org.uk](mailto:active@ageukoxfordshire.org.uk)

**Move.Me** Exercise class provided by Parkinsons.Me

Website: [www.parkinsons.me](http://www.parkinsons.me)

Phone 07729 801 048

**Oxford Neurology Physiotherapy (ON Physio)**

Self-funded specialist physiotherapy for people with neurological conditions. Small group classes offered specifically for people with Parkinson's. Some of the physios are PD Warrior instructors.

Website: [www.onphysio.co.uk](http://www.onphysio.co.uk)

Phone: 01865 817 656

## Useful contacts

### **Parkinsons UK**

Here you will find more information on Parkinson's and what local support there is available to you through your local PD UK Branch support group. There are support groups in Henley, Oxford and Banbury and Towcester & Daventry.

Helpline: 0808 800 0303

Website: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

### **Parkinson's Local Adviser – Oxfordshire**

Phone: 0344 225 3679

Email: [adviser.southeast@parkinsons.org.uk](mailto:adviser.southeast@parkinsons.org.uk)

#### **Covering the following districts**

- Vale of White Horse District Council.
- West Oxfordshire District Council.
- Cherwell District Council.
- Oxford City Council.

### **Parkinson's Local Adviser – Oxfordshire**

Phone: 0344 225 3675

Email: [adviser.southeast@parkinsons.org.uk](mailto:adviser.southeast@parkinsons.org.uk)

#### **Covering the following district:**

South Oxfordshire District Council

### **Parkinsons Local Adviser – West Northamptonshire**

Phone: 0344 225 3649

Email: [adviser.midlands@parkinsons.org.uk](mailto:adviser.midlands@parkinsons.org.uk)



## **Parkinsons UK Local Advisors**

Parkinson's UK can sign post you to local PD UK advisors by contacting their helpline (as above) or

Email: [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

## **Oxford Branch of Parkinson's UK**

Website: [www.oxfordparkinsons.org.uk](http://www.oxfordparkinsons.org.uk)

Phone: 0300 772 7003

## **Banbury Branch of Parkinson's UK**

Email: [parkinsonsbanbury@gmail.com](mailto:parkinsonsbanbury@gmail.com)

## **Parkinsons.Me**

(local charity with a friendly community garden)

Website: [www.parkinsons.me](http://www.parkinsons.me)

Phone: 07729 801 048

## **Oxfordshire Social Services**

(for self-referrals for equipment at home, Occupational Therapy input and assessments such as financial care assessments from a Social Worker)

Phone: 0345 050 7666

**More details on how to contact your local Parkinson's Nurse Specialist can be found in the leaflet 'Oxfordshire Parkinson's Nurse Specialist Service'.**



## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Leaflet updated by Jo Bromley & Nic Findlay  
(Community Neurology Nurse Specialists) V2 March 2024

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Oxford University Hospitals NHS Foundation Trust

[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)



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