

Movement Disorders Group (Parkinson's disease)

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 both people who are newly diagnosed and people who are already living with Parkinson's disease, who live in Oxfordshire and South Northamptonshire. It contains useful resources, such as:

- contact details for the local Parkinson's Disease Nurses
- symptoms and medicine management information
- details of the regular Review Pathway.

WHAT IS PARKINSON'S DISEASE?

Parkinson's disease (PD) affects the cells (neurons) in the brain responsible for the release of dopamine, which is chemical neurotransmitter that helps your body to move.

Dopamine sends messages to the body to help control movements, but this action is affected when you have Parkinson's disease.

It is very important to remember that Parkinson's disease affects people in many different ways. Your symptoms and treatment may be different to other people with Parkinson's.

SYMPTOMS YOU MAY EXPERIENCE

You may experience the following MOTOR symptoms:

- tremor
- rigidity (muscle stiffness)
- slowness of movements (bradykinesia).

Some other NON-MOTOR symptoms you may experience:

- balance problems – you may be at more risk of falls
- nerve pain
- urinary incontinence (leaking of urine) or constipation
- swallowing difficulties (dysphagia)
- sleep disorders
- speech difficulties
- changes in mood
- anxiety.

COMMON DESCRIPTIONS OF SYMPTOMS

- **On** – at your best
- **Off** – at your worst
- **Dyskinesia** – too much movement
- **Freezing** – suddenly temporarily unable to move
- **Wearing off** – your medication has less effect and your symptoms worsen before your next dose
- **Gait** – a manner of walking
- **Tremor** – uncontrollable, involuntary movements, mostly when you're at rest.

YOUR REFERRAL REVIEW PATHWAY

1. Referral

Referral from your GP or another medical specialist to a Parkinson's disease Specialist Consultant or a Neurology/Geratology Consultant



2. Appointment with the Neurologist or Geratologist at the John Radcliffe Hospital

- Your diagnosis is made and you will be referred to your local Parkinson's Disease Specialist Nurse



3. Review with Parkinson's Disease Specialist Nurse within 6 to 8 weeks after your diagnosis

- You will receive a Parkinson's Disease information pack
- You will also be referred to the to the Multidisciplinary Team



4. If required, you will be referred for:

- the First Step Programme – a support group run by people with Parkinson's in your local area
- appointments with therapists, such as:
 - Physiotherapists (PT)
 - Occupational Therapists (OT)
 - Speech and Language Therapists (SALT)
 - Dietitians
 - Social Services

Let your nurse know if you need any of these services



5. Regular clinics near you:

- **Once a year (or more frequently if needed) – your Specialist Nurse**
- **Once a year – your Consultant**

*(Your Specialist Nurse may see you at home **if needed**. You are encouraged to contact your Specialist Nurse yearly or more frequently, depending on your needs.)*

MEDICATION MANAGEMENT



Take your medication on time and regularly, to help manage your symptoms effectively.

- Your medication is managed according to your symptoms.
- Never suddenly stop your treatment, as this can cause side effects. You should discuss this with your Specialist Nurse or Consultant.

TYPES OF TREATMENTS

Your specialist may prescribe your medication depending on your symptoms.

You are likely to be prescribed oral medication (tablets or liquid), such as:

- co-beneldopa (Madopar)
- co-careldopa (Sinemet)
- rotigotine (Neupro)
- ropirinole (Requip)
- rasagiline (Azilect)
- selegiline (Eldepryl/Zelapar)
- pramipexole (Mirapexin)

OTHER ADVANCED THERAPIES

Your specialist will discuss these other therapies with you, if they are required in the advanced stages.

- DBS – Deep Brain Stimulation (a surgical procedure)
- apomorphine, given by infusion/injection
- Duodopa – a form of medication (levodopa and carbidopa) which is given through a tube into the lower gut.

YOUR OXFORDSHIRE PARKINSON'S SPECIALISTS

You will be seen by either:

- a Geratologist OR Neurologist, who may be a specialist in Parkinson's disease/movement disorders.

MEET THE OXFORDSHIRE PARKINSON'S DISEASE SPECIALIST NURSE SERVICE

The Oxfordshire Parkinson's disease Specialist Nurse Service is a point of contact and support for you, your family and carers, and also your GP and hospital doctors and nurses.

HOSPITAL PARKINSON'S DISEASE SPECIALIST NURSE



Mabel Eghaghe

Tel: **01865 234 048**

Administrator Office: **01865 231 295**

Address: Neurosciences offices, West Wing,
Level 3, John Radcliffe Hospital

COMMUNITY PARKINSON'S DISEASE SPECIALIST NURSES



Jo Bromley

Tel: **01865 737 225**

Address: Community Neurology Specialist Nurse
Service, OCE, Nuffield Orthopaedic Centre,
Windmill Road, Oxford

Covering: Wheatley, Cumnor (city), West, Vale,
South Oxfordshire



Nicola Findlay

Tel: **01865 737 368**

Address: Community Neurology Specialist Nurse
Service, OCE, Nuffield Orthopaedic Centre,
Windmill Road, Oxford

Covering: North Oxfordshire and South
Northamptonshire

ACTIVITIES IN YOUR LOCAL AREA

Exercise is medicine!

A regular physical activity will help improve your gait, your mood and your balance.

- **Big, Bold and Balance, Age UK**
Tel: 01235 849 403
- **Henley Parkinson's Disease Exercise Class** (Private class)
Tel: 07766 666 551
- **Neurological Disability Gym Session, Age UK**
Tel: 01235 849 403
- **Oxford Neurology Physiotherapy Exercise Class at the Bosworth Clinic**
Tel: 01865 881 334
- **Generation Games – Age UK**
Oxfordshire activities for over 50's.
Tel: 01235 849 403
Website: www.generationgames.org.uk

Dance for Parkinson (D4P)

Weekly dance activities for people with Parkinson's, their friends and families.

Tel: 01865 252 820

Website: www.danceforparkinsonsuk.org

Pilates

- **The Oxford Physiotherapy Service**
Tel: 01865 311 686 or
Email: hello@oxphys.co.uk
- **Millstream Pilates Oxfordshire** (Private class)
Tel: 07801 298 978

Mindfulness

To help you learn how to cope with daily routines.

- **Mindfulness Based Cognitive Therapy** – referral needed by your consultant, specialist nurse or GP.

For more information, contact **Talking Space Plus**.

Tel: 01865 901 222

TIPS FOR DAILY LIVING

Set up a '**medication reminder**'. You may want to consider an alarm such as:

- an alarm clock
- talking watch
- digital tablet/clock.

When coming for your clinical appointment, please remember to bring the following:

- a list of your current medication
- a diary of the symptoms you experience
- any questions you wish to discuss.

Difficulties with writing/typing:

- Think **big** and write with **bold** letters.
- Take your time.
- Use an 'app' for text messages. If you have a smartphone, download an app called 'Dragon Dictation' which allows you to speak and hear your messages.

USEFUL CONTACTS

Parkinson's UK

Helpline: 0808 800 0303 – free and confidential service and support

Parkinson's UK Local Adviser Oxfordshire

Tel: 0344 225 3679

Parkinson's UK South Oxfordshire

Tel: 0344 225 3677 or 0344 225 3758

Social Services ACCESS Team (including Occupational Therapy)

You and your carers can self-refer to these services.

Tel: 0845 050 7666

"I wish my wife had been given the opportunity to speak to someone much earlier. A lot of anguish and anxiety could have been avoided.

My wife has since seen a specialist who gave her the assurance she desperately needed"

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

USEFUL WEBSITES

Parkinson's UK

Website: www.parkinsons.org.uk

Oxford Branch of Parkinson's UK

Website: <https://oxfordparkinsons.org.uk>

Parkinsons.me

Website: www.parkinsons.me

Email: info@parkinsons.me

A charity providing support and advice.

PD Warrior Exercise programmes (videos)

Website: <https://pdwarrior.com>

FINDING EQUIPMENT

Living made easy

Website: www.livingmadeeasy.org.uk

Parkinson's UK shop

Website: www.parkinsons.org.uk/shop

TAKE PART IN RESEARCH

Oxford Parkinson's Disease Centre

Website: www.opdc.ox.ac.uk

Stay informed about the latest research. OPDC was created in 2010 to unite scientists and their work on Parkinson's Disease.

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALS@ouh.nhs.uk**

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