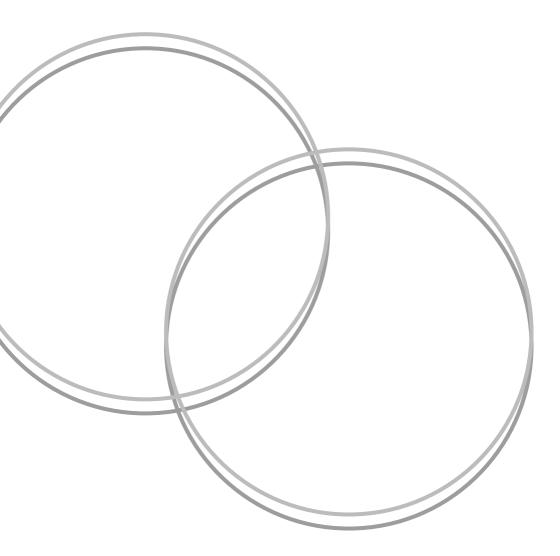


Oxfordshire Parkinson's Specialist Nurse Service

Information for patients



Introduction

This leaflet has been written for people referred to the Parkinson's Nurse Service, who are living with Parkinson's and Atypical Parkinsonism in Oxfordshire and South Northamptonshire.

It's important to remember that people experience Parkinson's in different ways and symptoms and treatment may be different to other people.

Parkinson's Specialist Nurse Service

We provide support for people who have a confirmed diagnosis of Parkinson's across Oxfordshire and South Northants in local Nurse led clinics and where appropriate at home.

We work closely with the Neurologists and Geriatricians in the OUH and other Trusts to provide shared care. We also consult closely with health and social care professionals in your area (such as your GP).

Parkinson's Specialist Nurse-led clinics

Parkinson's Nurse-led clinics are held in:

Abingdon	Brackley	Faringdon
Bicester	Banbury	Wantage
Chipping Norton	Didcot	Wallingford
Witney	Oxford City (at the John Radcliffe Hospital)	

How do I get referred to a Parkinson's Nurse?

If you are newly diagnosed, your consultant will usually refer you directly to the relevant Parkinson's Nurse for your area at the time you are diagnosed. We do also accept referrals from other health and social care professionals such as your GP.

How often will the nurse see me?

We aim to review you between your consultant appointment typically 6 to 12 monthly; this will be decided with you on an individual basis. If you require support in between your routine appointments, please do not hesitate in contacting us sooner.

At your appointment with your nurse

- Take someone with you if possible.
- Make a list of things you wish to discuss and bring it with you.
- Bring a list of medications your taking including over the counter medications and supplements.
- Keep a diary of your symptoms if possible.
- Sometimes we may need ask you to read or write something as part of the assessment we do. If you wear glasses to read, please bring these with you.

Useful advice

What happens if my Parkinson's symptoms change suddenly?

Parkinson's symptoms are usually slowly progressive. If you have a very sudden change in symptoms (such as within a few days or a week) there may be an underlying cause. Common reasons for this could be, constipation, infection, dehydration, medication changes or changes in personal circumstances. It can take some time once the underlying problem has resolved for the Parkinson's symptoms to return to previous levels. If you are concerned, please speak to your Parkinson's Nurse Specialist or GP.

If you have any concerns regarding any other health related issues, please contact your GP first in the usual way.

How do I get support with my Parkinson's out of hours or over a weekend or bank holiday?

If you have a problem with your Parkinson's symptoms out of hours, weekends or Bank Holidays that cannot wait until the Nurses are available during their working days/hours, please seek medical advice via: **Ringing NHS 111 or in an emergency call 999**

What do I do if I have to go into hospital?

If you are admitted to hospital planned or as an emergency, take all your medication in the original packets, named, and labelled. This is especially important with any medication relating to your Parkinson's. These are not always stocked routinely on wards and may need to be ordered from the hospital pharmacy.

Mabel Eghaghe is also our inpatient Parkinson's Nurse Specialist. If needed, the ward can contact Mabel for advice about your Parkinson's during your inpatient stay. Alternatively, the on-call liaison neurology team can also offer inpatient advice.

Getting Parkinson's medication 'on time' – The OUH is committed to supporting the Parkinson's UK 'Get It ON Time' campaign.

Where can I find more information on Parkinson's?

Parkinson's UK:

Website: <u>www.parkinsons.org.uk</u> Helpline: 0808 800 0303 For those people diagnosed with an Atypical type of Parkinsonism, the following charities have really useful websites:

Multiple System Atrophy (MSA) Trust:

Website: <u>www.msatrust.org.uk</u> Helpline: 0333 323 4591

Progressive Supranuclear Palsy (PSP) Association:

Website: <u>www.pspassociation.org.uk</u> Helpline: 0300 0110 122

Corticobasal Degeneration (CBD/CBS):

Website: <u>www.pspassociation.org.uk/information-and-support/</u> what-is-cbd Helpline: 0300 0110 122

Further information specific to your Parkinson's is available at either your review with your Nurse or Consultant.

What is available to support me in the local area?

Parkinson's UK Helpline

Helpline enquiries you may wish to contact the freephone helpline on 0808 800 0303. It is open Monday to Friday, 9am to 6pm and Saturday, 10am to 2pm.

Parkinson's Local Adviser – Oxfordshire

Phone: 0344 225 3679 Email: <u>adviser.southeast@parkinsons.org.uk</u>

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: <u>adviser.southeast@parkinsons.org.uk</u>

Covering the following district:

• South Oxfordshire District Council.

Parkinsons Local Adviser – West Northamptonshire

Phone: 0344 225 3649 Email: <u>adviser.midlands@parkinsons.org.uk</u> Page 7

Parkinson's UK Oxford Branch

Website: www.oxfordparkinsons.org.uk Phone: 0300 772 7000

Parkinson's UK Banbury Branch

Email: parkinsonsbanbury@gmail.com

Parkinsons.Me

(Oxfordshire based) Website: <u>www.parkinsons.me</u>

Exercise Classes provided by Age UK Oxfordshire

(including 'Big Bold and Balance' for people living with Parkinson's amongst many other classes) Phone: 01235 849 403 Email: <u>active@ageukoxfordshire.org.uk</u>

Social Prescribers Often based at GP practices and can provide useful information on local activities and support with housing, benefits, and financial support. Phone: 01235 849 434

How to contact your Parkinson's Nurse Specialist

Hospital Inpatient support and Oxford City outpatient support:

Mabel Eghaghe

Telephone:	01865 234 048
Admin:	01865 231 295 (Neurology)
	01865 234 848 (Geratology)
Address:	Neurosciences Offices, West Wing, Level 3, John Radcliffe Hospital, Headley Way, Oxford OX3 9DH

Neurology Nurse Specialists (community based):

JO Bromley	Hannah Fullam
Nic Findlay	Sue Hill

Covering all other areas including South Northamptonshire, North, West and South Oxfordshire and Vale of the White Horse.

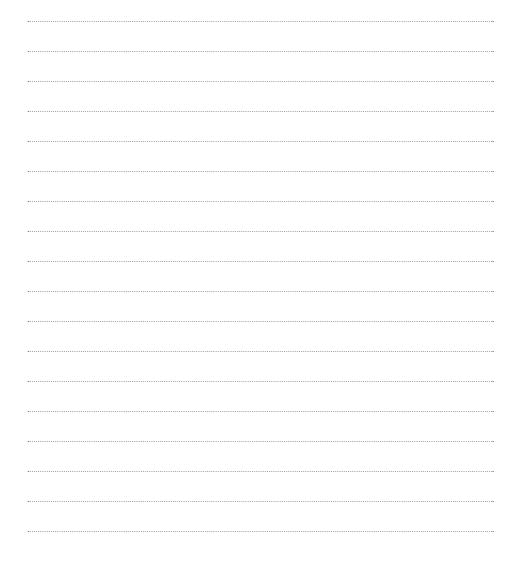
Telephone: 01865 737 465

Email: <u>communityneurologynurses@ouh.nhs.uk</u>

Address: Community Neurology Specialist Nurse Service, OCE, Nuffield Orthopaedic Centre, Windmill Road, Oxford OX3 7HE If you have been told you may have a diagnosis of Atypical Parkinsonism such as MSA, PSP or CBD your Specialist Nurse will be either Jo, Nic, Sue or Hannah.

My Specialist Nurse is:

Notes:



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 compiled by Jo Bromley and Nic Findlay (Community Neurology Specialist Nurses) March 2024 December 2024 Review: December 2027 Oxford University Hospitals NHS Foundation Trust www.ouh.nhs.uk/information



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