

## Additional Notes



University Hospitals Dorset  
NHS Foundation Trust




# Parkinson's nurse specialist service

The Royal Bournemouth Hospital,  
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Neurology department  
**Patient information**

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## What is Parkinson's?

Parkinson's is a progressive neurological condition, meaning that it occurs in the brain and it gets worse over time. It affects the cells in the brain responsible for the release of dopamine. Dopamine is a chemical that helps your body to move.

Parkinson's affects people in many different ways. Your symptoms and treatment may be different to other people with Parkinson's.

## What symptoms may I have?

You may experience the following physical or motor symptoms:

- muscular rigidity or stiffness
- slow movement (bradykinesia)
- shaking of a particular part of the body (tremor)

You may experience other physical or psychological symptoms such as:

- balance problems which may increase the chances of a fall
- nerve pain
- constipation
- memory problems
- swallowing difficulties
- speech difficulties
- mood changes
- anxiety
- sleep problems

- **Wearing off** - your medication has less effect and your symptoms worsen before your next dose

## Friends and family test

Please tell us how the Parkinson's nurse team are doing through the friends and family test. Tell us what is working and what we can do better. Your comments will help us plan improvements to the care we provide.

To complete the form online visit **[www.uhd.nhs.uk](http://www.uhd.nhs.uk)** search 'friends and family test'



- hallucinations/misperceptions (seeing or hearing things that are not there)

**Do not abruptly stop medication** without first discussing it with a healthcare professional.

## Who are the Parkinson's nurse specialists?

We are a team of experienced nurses who specialise in the care of people affected by Parkinson's. We are part of a multidisciplinary team and act as a link between you, your GP and consultant, and other services.

## What service does the Parkinson's nurse service offer?

We can offer:

- support and information about Parkinson's and the treatments available
- specialist nursing assessment and advice on how best to manage your Parkinson's symptoms, this may include medication changes
- on-going education and support for you, your relatives and carers
- links to other services that can help you

We work closely with the neurology and older person's medicine consultants as well as general practitioners (GPs), district nurses, occupational therapists, physiotherapists, speech and language therapists, pharmacists and social workers.

## For further information about Parkinson's contact:

### Parkinson's UK

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

Telephone: **020007318090**

Freephone helpline: **0808 800 0303**

Monday to Friday: 9am until 6pm

Saturday 10am until 2pm

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

Produced by Parkinson's UK, first steps is an online programme for people recently diagnosed with Parkinson's and their family, friends and carers.

[First Steps programme | Parkinson's UK \(parkinsons.org.uk\)](http://www.parkinsons.org.uk)

### The Cure Parkinson's Trust

Email: [info@cureparkinsons.org.uk](mailto:info@cureparkinsons.org.uk)

Telephone: **0207 487 3892**

**[www.cureparkinsons.org.uk](http://www.cureparkinsons.org.uk)**

### Parkinson's local groups

For more information about groups or events local to you please ask the Parkinson's nurse Specialist or look at the Parkinson's UK website and search for the full list of local groups.

## Commonly Used Medical Terms in Parkinson's:

- **Akinesia** - loss of ability to move muscles voluntarily
- **Bradykinesia** - slowing of voluntary movements
- **Cognitive processes** -mental processes involving thinking and memory
- **Dyskinesia** - involuntary movement
- **Dysphagia** - swallowing difficulties
- **Freezing** - suddenly temporarily unable to move
- **Gait** - a manner of walking
- **Hallucinations** -when a person sees, hears, feels or tastes something that doesn't exist
- **Hypomimia** - lack of facial expression
- **Hypophonia** - quiet speech
- **Impulsive Control Disorder** - behaviour resulting from an uncontrollable need to perform a particular action
- **ON** - you feel at your most able and that the drugs are working
- **OFF** - you feel unable to move or function as normal and feel that the medication isn't working
- **Rapid Eye Movement (REM) sleep disorder** - acting out of dreams that may be vivid, intense or violent
- **Restless leg syndrome (RLS)** - uncomfortable or unpleasant sensations in your legs and an irresistible urge to move them
- **Sialorrhea** - drooling or excessive salivation
- **Tremor** - an involuntary quivering movement, mostly at rest.

## What treatments are there for Parkinson's?

At present there is no known cure for Parkinson's. However, scientific advances have increased our understanding of Parkinson's and how best to treat individuals to reduce the symptoms.

Medications can improve your symptoms and your quality of life. Parkinson's is individual in terms of which medications you may need and at what time you may need to take them. Treatment is usually life-long with changes occurring as your symptoms change and the Parkinson's progresses.

You should take your medication on time and regularly to manage your Parkinson's symptoms.

## What happens when my Parkinson's treatment is changed?

When treatments for Parkinson's disease are changed, most people notice an improvement in their symptoms. Occasionally, a change in medication can cause a worsening of symptoms, particularly if a dose has been reduced. If the dose has recently been increased or a new treatment started, the risk of side effects is higher.

Common side effects include:

- nausea and vomiting
- feeling dizzy or lightheaded (sometimes due to low blood pressure)
- feeling tired and sleeping excessively during the day
- involuntary movements (dyskinesia)
- confusion

- you have developed side effects from the Parkinson's medication.

## How do I contact the Parkinson's nurse specialists?

You can contact the Parkinson's nurse specialists on:

Telephone: **0300 019 8012** 8:30am to 4:30pm Monday to Friday

Email: **parkinsons.service@uhd.nhs.uk**

Please ensure that you leave your name, date of birth, hospital number and a short message giving the reason for your call. Your call may be answered by the team's administrator who may require further information and will arrange further contact with a nurse if required. This contact is likely to be a telephone appointment in the first instance. A face to face appointment will be made if necessary.

## What should I bring to my appointment with the Parkinson's nurse?

Please remember to bring:

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

You are welcome to have someone accompany you to the appointment

## When should I contact my GP?

You should contact your GP surgery for the following:

- renewal of prescriptions
- results of investigations including brain scans and blood tests
- sudden changes in your condition physiotherapy or occupational therapy local referral
- and any other medical problems

## When should I contact the Parkinson's nurse specialist service?

The Parkinson's nurse specialist helpline is **not** an urgent care service. If you require urgent medical advice, you should contact your GP, NHS **111**, your local walk-in centre or, if you are really unwell, your local Emergency Department.

Sudden changes in your symptoms are not usually expected and are likely due to other factors such as infection, constipation, dehydration, medication changes or changes in personal circumstances. It is important that the underlying issue is identified and resolved to allow your Parkinson's symptoms to return to your previous levels.

## Useful contacts:

### Social Services

If you require help with domestic tasks or any social issues and benefits please contact the Social Services specific to your local area:

Poole	<b>01202 633902</b>
Bournemouth	<b>01202 454979</b>
Purbeck	<b>01929 553456</b>
Ferndown	<b>01202 877445</b>
Dorset	<b>01305 221016</b>

### Driving

You must inform the DVLA and your car insurance of your diagnosis. For car or motorcycle driving licence renewal queries:

Telephone: **0300 790 6806** Monday to Friday 8am until 7pm  
Saturday 8am until 2pm

The Parkinson's specialist nurses are not able to complete driving licence renewal forms. These forms must be completed by either your GP or consultant, whoever you have seen most recently to discuss your Parkinson's.

## Where can I see the Parkinson's nurse specialist?

We have clinics located in Poole, Wimborne, Swanage and Christchurch. Home visits are only offered for housebound patients who are unable to attend clinic appointments.

## How frequently will I see the Parkinson's nurse specialist?

A Parkinson's nurse specialist will contact you following your diagnosis and an appointment will be made to see you in a clinic or for a telephone consultation. Following this appointment, you may be asked to be put on a patient initiated follow up pathway. **Patient initiated follow up (PIFU)** allows you to arrange follow up appointments as and when you need them.

The reason we offer follow up this way is because we want to give you more choice and flexibility and reduce unwanted and unnecessary visits to the hospital. This will help improve your experience, reduce your cost of travel and parking, and reduce waiting times for appointments.

**If you have not made contact after a year from your last review, we will make an appointment to see you.**

## You should contact the Parkinson nurse specialist if:

- you develop worsening of Parkinson's symptoms and your GP has ruled out other causes such as an infection, constipation, or dehydration.
- the Parkinson's medication is no longer managing your symptoms effectively.