

Additional Notes

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To ask for this leaflet in larger print, please contact the patient experience team on **0300 019 8499** or email uhd.patientexperienceteam@nhs.net.

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Some of our hospital services are moving.
Visit www.uhd.nhs.uk/future to find out more.

Parkinson's Service



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Neurology department
Patient information

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What is Parkinson's?

- Parkinson's is a condition that affects the brain and gets worse over time.
- People with Parkinson's don't have enough of a chemical in the brain called dopamine. This is because some nerve cells that make it have stopped working.
- Parkinson's affects everyone differently. Symptoms and treatments can be different for each person.

What symptoms may I have?

You may experience the following physical, or **motor**, symptoms. A motor symptom is one that affects **movement**:

- stiff or rigid muscles
- slow movement (called bradykinesia)
- shaking in parts of the body (tremor)

You may also experience **non-motor symptoms**.

A non-motor symptom is a symptom that **does not involve movement**. Symptoms may include:

- balance problems, which may increase the chances of a fall
- nerve pain
- constipation
- memory problems
- trouble swallowing or speaking
- mood changes like anxiety or depression
- sleep problems

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.

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 Service 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 search Friends and Family test.

Who are the Parkinson's specialist practitioners?

We are a team focused on Parkinson's care. We work with your GP, consultants, and other therapists.

We can:

- give advice and support
- help manage symptoms and medicines
- connect you with other services

Where can I see the Parkinson's specialist practitioner?

We have clinics in Poole, Wimborne, Swanage, Bournemouth and Christchurch. Home visits may be offered if you are unable to travel to a clinic appointment.

How often will I see the Parkinson's specialist practitioner?

After your diagnosis you will have a clinic appointment. After that, you usually return once a year. You can also use something called 'patient initiated follow up (PIFU)', which lets you get advice or support whenever you need it.

What should I bring to my appointment?

Please bring:

- a list of your medicines
- a diary of your symptoms
- any questions
- a friend or family member if you want

Social Services

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

- Poole - **01202 633902**
- Bournemouth - **01202 454979** (Care Direct)
- Christchurch - **01202 474106**
- Ferndown - **01202 877445**
- Purbeck - **01929 553456**

**For all out of hours emergencies call:
Social Services - 01202 657279**

Pendant Alarms - provide an emergency contact system for people living at home.

- Poole Lifeline - **01202 733255**
- Bournemouth Care-line - **01202 452795**
- ASTER (rest of Dorset) - **0845 6014322**

Carer's Support

Caring for someone in the Bournemouth, Christchurch or Poole (BCP) council area please contact:

BCP Carer Support

Email: carersupport@bcpcouncil.gov.uk

Telephone: **01202 128787**

Caring for someone in the Dorset council area please contact:

Carer Support Dorset

Email: admin@carersupportdorset.co.uk

Telephone: **0800 368 8349**

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

What treatments are there for Parkinson's?

There is no cure yet. Medicines can help control symptoms and improve daily life.

- Treatment usually lasts for life.
- Medicines may change as symptoms change.
- It's important to take medicine on time and regularly.

What happens when my Parkinson's treatment is changed?

When medicine is changed, symptoms often improve. Sometimes side effects appear, especially with new or higher doses.

Possible side effects include:

- feeling sick (nausea, vomiting)
- dizziness which may be linked to low blood pressure
- feeling very tired or sleepy in the day
- uncontrolled movements (dyskinesia)
- confusion
- hallucinations (seeing or hearing things that aren't real)

Never stop Parkinson's medicines suddenly without talking to a doctor.

When should I contact my GP?

You should contact your GP surgery for the following:

- to renew prescriptions
- for test results (like scans or blood tests)
- if your Parkinson symptoms suddenly change
- for therapy referrals (physio, speech, occupational)
- for other medical problems

Driving

After being diagnosed with Parkinson's, you need to tell the DVLA and your car insurance company. For car or motorcycle driving licence renewal queries:

Telephone: **0300 790 6806**

Monday to Friday 8am until 7pm

Saturday 8am until 2pm

Parkinson's Specialist practitioners cannot fill in driving licence renewal forms. These must be completed by your GP or consultant, whichever you saw most recently about your Parkinson's.

What happens if I go into hospital?

It is useful to bring:

- a list of medicines and times
- medicines in their boxes

Parkinson's medicine must be taken at the same times as at home. Do not stop suddenly.

Inpatient carer's support

The Carer Support Service helps carers and can point them to community support after leaving the hospital.

Carers can contact the service themselves or ask a staff member to make a referral. If a carer is admitted to the hospital, they can also use the service.

Telephone: **0300 019 8714**

Monday to Friday 9am to 3pm

Email: **uhd.carersupport@nhs.net**

Ask: a member of staff for a carer referral

Useful contacts:

Parkinson's UK

Email: hello@parkinsons.org.uk

Helpline: **0808 800 0303**

Monday to Friday: 9am until 6pm

Saturday 10am until 1pm

www.parkinsons.org.uk

The Cure Parkinson's Trust

Email: info@cureparkinsons.org.uk

Telephone: **0207 487 3892**

www.cureparkinsons.org.uk

Local Parkinson UK groups

There are local branches for East Dorset, Christchurch and Poole districts. Details of local meetings and exercise classes or activities can be found on the Parkinson's UK website.

Mental wellbeing

You do not need to be referred by your GP or other health professional, you can refer yourself to these services.

- **Connection** - a 24/7 helpline open to all ages. Dorset residents or people visiting Dorset can call **0800 6520190** or NHS 111 for free.
- Our local **NHS Talking Therapies service** is: www.steps2wellbeing.co.uk or call **0800 484 0500**
- **'Help & Care'** is an organisation that focusses on supporting people with long term conditions and their carers/families: www.helpandcare.org.uk or call **0300 111 3303**

When should I contact the Parkinson's Service?

Sudden changes in your symptoms are not usually expected. You should contact our service if your:

- symptoms get worse. Please see your GP first to rule out other causes like infection, constipation, or dehydration.
- the Parkinson's medicine no longer works well
- you have side effects from the Parkinson's medication.

The Parkinson's Service email and advice line is not an urgent care service. If you need urgent medical help, contact your GP, NHS 111, a walk-in centre, or go to the Emergency Department if you are very unwell.

How do I contact the Parkinson's Service?

You can contact the Parkinson Service on:

Telephone: **0300 019 8012**

8.30am to 4.30pm, Monday to Friday

Email: uhd.parkinsons.service@nhs.net

Please leave your name, date of birth, hospital number, and a short message explaining why you are calling.