

# Parkinsonism

**P**arkinsonism is an umbrella term used to cover a range of conditions. These conditions share the symptom of slow movement, sometimes with tremor, rigidity and problems with walking.

This information sheet describes the different forms of parkinsonism and explains how parkinsonism is diagnosed. It also looks at the methods your specialist may use to work out which form of parkinsonism you have.

## What are the different forms of parkinsonism?

Most people with a form of parkinsonism have idiopathic Parkinson's disease, also known as Parkinson's. Idiopathic means that the cause is unknown.

People showing symptoms of parkinsonism who are not diagnosed with idiopathic Parkinson's may have another type of parkinsonism.

Forms of parkinsonism that are currently recognised, other than Parkinson's, include the following:

### **Multiple system atrophy (MSA)**

Both multiple system atrophy and Parkinson's cause stiffness and slowness of movement in the early stages. People with multiple system atrophy can also develop symptoms such as incontinence, difficulty with swallowing and dizziness. These symptoms are unusual in early Parkinson's. The condition used to be known as striatonigral degeneration, Shy-Drager syndrome, or olivopontocerebellar atrophy.

### **Progressive supranuclear palsy (PSP)**

Progressive supranuclear palsy affects eye movement, balance, mobility, speech and swallowing. It is sometimes called Steele-Richardson-Olszewski syndrome.

### **Normal pressure hydrocephalus**

The symptoms of normal pressure hydrocephalus mainly affect the lower half of the body. The common symptoms are walking difficulties, urinary incontinence and memory problems. Removing some cerebrospinal

fluid can help with these symptoms in the short term. If there is improvement after this procedure, an operation to divert the spinal fluid permanently (known as lumbar puncture) can help in the long term.

### **Vascular or arteriosclerotic parkinsonism**

Vascular parkinsonism affects people with restricted blood supply to the brain, usually older people who have problems such as diabetes.

The symptoms of vascular parkinsonism are often the same as normal pressure hydrocephalus (above), but they can't be improved by lumbar puncture.

Some people with vascular parkinsonism may swing their arms less than those with Parkinson's. Sometimes, people who have had a stroke, often one so mild that they didn't notice it, may experience this form of parkinsonism.

### **Drug-induced parkinsonism**

Some drugs can cause a form of parkinsonism, which is usually reversible.

**Find out more:** see our information sheet *Drug-induced parkinsonism*.

There are several other, much rarer, possible causes of parkinsonism.

There are also some other conditions that have symptoms similar to those seen in parkinsonism. Your specialist may wish to rule out rare conditions such as Wilson's disease, an inherited condition where there is too much copper in the body's tissues.

### **Various tremors, including essential tremor, dystonic tremor, indeterminate tremor and atypical tremor**

You may be diagnosed with one of these conditions if tremor is your main symptom and it is not caused by Parkinson's.

**Find out more:** see our information sheet *Tremor and Parkinson's*.

## **How is parkinsonism diagnosed?**

You should be referred to a Parkinson's specialist for diagnosis. They will look at your medical history, carry out a detailed neurological interview and medical examination.

### **Investigating symptoms**

Specialists who see a lot of people with parkinsonism may notice unusual symptoms that lead them to diagnose a form of parkinsonism that is not Parkinson's. But differentiating between types of parkinsonism is not always easy, because:

- the first symptoms of the different forms of parkinsonism are so similar
- in many cases, parkinsonism develops gradually. Symptoms that allow your doctor to make a more specific diagnosis may only appear as your condition progresses
- everyone with parkinsonism is different and has different symptoms

### **Response to Parkinson's drugs**

One of the most useful tests to find out what sort of parkinsonism you may have is to see how you respond to treatment. If your specialist thinks you might have Parkinson's, they will expect you to have a good response to Parkinson's drugs, such as levodopa (co-careldopa or co-beneldopa). A good response means that your symptoms will improve, as long as a large enough dose is given that lasts for a long enough time. Sometimes, it will only be clear that you've responded to medication when the drug is reduced or stopped,

and your symptoms become more obvious again. If you don't have any response to Parkinson's medication, it will mean that your Parkinson's specialist will have to look again at your diagnosis.

Most people with forms of parkinsonism other than Parkinson's usually don't respond, or respond less well, to Parkinson's drugs. But to confuse things, some people with forms of parkinsonism other than Parkinson's will show some response.

If you have both unusual symptoms and no response to Parkinson's drugs, this doesn't automatically mean you have another form of parkinsonism. But it will make your specialist want to investigate further.

In this case, your specialist may use the terms 'atypical parkinsonism' or 'Parkinson's plus'. These terms are not a diagnosis, but they simply mean that you probably have something other than Parkinson's.

### **Specialist tests**

Although they are not routinely available, there are specific tests that your specialist may wish to carry out. None of these tests alone can make a definite diagnosis, but sometimes they can rule out a particular condition. Sometimes (used alone or combined with other tests) they may help strengthen a case for a particular diagnosis, but only when put together with your medical history and the results from your medical examination.

Current tests available include:

- a dopamine transporter chemical scan, known as a Dat Spect Scan or DaTSCAN, or an FP-CIT scan
- lumbar puncture (an operation to divert spinal fluid) or cerebrospinal fluid infusion testing (which tests the ability for cerebrospinal fluid to be absorbed)
- MRI (magnetic resonance imaging) brain scanning
- an electrical recording (EMG) of the urethral or anal sphincter. This test checks the health of the muscles and the nerves that control them
- special recordings of pulse and blood pressure, known as autonomic function tests (AFTs). Dizzy spells and low blood pressure can be a sign of multiple system atrophy

**Find out more:** to read more about MRIs and DaTSCANS, see our information sheet *Diagnosing Parkinson's*.

## More information and support

It can be unsettling if you think you have Parkinson's, but are then told you may not have this condition. You may feel like you're in limbo while waiting for the new diagnosis, but there are people who can help.

Speak to your GP or specialist. You can also speak to your Parkinson's nurse, if you have one.

If you have been diagnosed with a benign tremor condition, multiple system atrophy or progressive supranuclear palsy, the following organisations can also offer more specific support.

### **The National Tremor Foundation**

**01708 386399**

**[enquiries@tremor.org.uk](mailto:enquiries@tremor.org.uk)**

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

### **The Multiple System Atrophy Trust**

**0333 323 4591**

**[support@msatrust.org.uk](mailto:support@msatrust.org.uk)**

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

### **The PSP Association**

**01327 322410**

**[psp@pspeur.org](mailto:psp@pspeur.org)**

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

### **Parkinson's nurses**

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **[parkinsons.org.uk/nurses](http://parkinsons.org.uk/nurses)**

## Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

Visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

## Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

**Richard Grunewald, Consultant Neurologist, Royal Hallamshire Hospital, Sheffield**

**Gina Robinson, Senior Lecturer, Northumberland University**

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

## Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

## Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**



## Parkinsonism (2014)

If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at **publications@parkinsons.org.uk**. Thanks!

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other .....

How useful have you found the information sheet? (1 is not useful, 4 is very useful) 1 2 3 4

Have you found the publication easy to read/use?  Yes  No

Has this resource given you information that might help you manage your condition better?

- NA
- It hasn't helped
- It has helped a little
- It has helped a lot

What aspects did you find most helpful? .....

Were you looking for any information that wasn't covered? .....

Do you have any other comments? .....

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- Membership
- Information review group (who give us feedback on new and updated resources)

Name .....

Address .....

Telephone ..... Email .....

- What is your ethnic background?  Asian or Asian British  Black or Black British  Chinese  Mixed  White British  White other  Other (please specify) .....

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day when no one fears Parkinson's.**

## **Parkinson's UK**

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **[www.ngts.org.uk](http://www.ngts.org.uk)**

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

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

Last updated August 2014. We review our information within three years.  
Please check our website for the most up-to-date versions of all our information.  
PKFS14

© Parkinson's UK. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).

