

Diagnosing Parkinson's

Current evidence suggests that Parkinson's tends to develop gradually and it may be many months, even years, before the symptoms become obvious enough for you to go to the doctor.

This information sheet looks at what parkinsonism is, how Parkinson's and other similar conditions may be diagnosed, and explains some of the tests that may be involved in the process.

What is Parkinsonism?

Parkinsonism is a term used to describe symptoms or signs that are found in Parkinson's, but which can also be found in other conditions that cause slowness of movement, stiffness and tremor.

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

Other less common forms of parkinsonism include multiple system atrophy (MSA), progressive supranuclear palsy (PSP), drug-induced parkinsonism and vascular Parkinson's.

Find out more: see our information sheet *Parkinsonism* and our leaflet *A quick introduction to Parkinson's*.

Who should I speak to if I think I might have Parkinson's?

If you are concerned about symptoms you have been experiencing, you should visit your GP. If your GP suspects you have Parkinson's, it is important you are referred to a Parkinson's specialist before any treatment is considered. The National Institute for Clinical Excellence (NICE) recommends you should see a specialist within six weeks. It is not always easy to diagnose the condition, so it's important that you see a Parkinson's specialist to get an accurate diagnosis and to consider the best treatment options.

How is Parkinson's diagnosed?

Confirming someone has Parkinson's can take some time as there are other conditions such as essential tremor (see page 3), with similar symptoms. There is also currently no definitive test for diagnosing Parkinson's.

Investigating symptoms

Parkinson's should be diagnosed after having a consultation with a specialist. A Parkinson's specialist will take a detailed neurological history and examine you. If you have been referred to a specialist, you may find it helpful to keep a diary or record of your symptoms to help you explain what's been happening to you.

There are many different symptoms related to Parkinson's and these can vary from person to person.

Early symptoms may include a reduced sense of smell, depression, anxiety, tiredness, disturbed sleep, memory loss and constipation.

Typical symptoms of Parkinson's may also include a tendency to have small handwriting, slowness of movement (bradykinesia), tremor, difficulty turning over in bed and fatigue. Your symptoms may also be made worse by stress or illness.

Looking for signs of Parkinson's

Your specialist will examine you to look for common signs of Parkinson's. You may be asked to:

- write or draw – to see if your writing is small or gradually fades
- walk – to see whether there is a reduction in the natural swing of your arm or in your stride length and speed
- speak – to see if your voice is soft or lacks volume

The specialist will also look at your:

- face – to see if there is a 'masked' look or if you have difficulty with facial expressions
- limbs – to see if you have a tremor, any stiffness (rigidity) or slowness of movement

As well as examining you to look for any of the typical signs of Parkinson's, the specialist will also look for any other signs that may suggest a different diagnosis. This is because there are other conditions that can cause similar symptoms to Parkinson's, such as essential tremor. This is described in more detail on page 3.

It may be helpful to take someone with you for support when seeing a specialist. Taking a list of questions you want to ask can also be useful so you don't forget to mention something you want to know about. If a healthcare professional says something you don't understand, don't be afraid to ask them to explain what they mean.

Response to Parkinson's drugs

After examining you, your specialist may suggest you take medication for Parkinson's. If your symptoms improve after taking Parkinson's medication for a few weeks or months, your specialist may confirm a Parkinson's diagnosis. However, some people with other forms of parkinsonism will also respond well to these drugs.

Other medical tests or scans that may confirm a diagnosis of Parkinson's

Your specialist may suggest you have a scan to help make a diagnosis. None of these scans alone can make a definite diagnosis of Parkinson's, so they are not commonly used.

MRI or CT scans

These are brain-imaging scans and can tell your specialist what the structure of your brain looks like. Brain scans of people with Parkinson's usually look normal, but can be helpful in diagnosing other types

“My GP told me I needed to see a neurologist and he told me he suspected Parkinson's. The Parkinson's specialist confirmed it and now I'm having treatment and feeling much better.”

Anne, diagnosed in 2009

of parkinsonism. The scan may not look normal in some of the rarer forms.

SPECT or DaTSCAN

These are scans that can tell your specialist how different areas of the brain are working. SPECT is a type of imaging test that shows how blood flows to tissues and organs. A certain type of SPECT scan has become widely used for helping specialists confirm the loss of a particular type of brain cell containing a chemical called dopamine. This type of scan is known as a dopamine transporter scan or DaTSCAN. It is the loss of these dopamine producing cells that causes the development of Parkinson's. But similar loss may also occur in some other rarer neurological conditions. So an abnormal DaTSCAN result cannot give a definitive diagnosis of Parkinson's.

A normal DaTSCAN can be helpful in showing that a person's symptoms, particularly tremor, are not caused by Parkinson's, but may be due to another condition, for example, essential tremor.

What is essential tremor?

A tremor is a rhythmical, involuntary movement that affects a part of the body, for example, the hand.

Essential tremor is the most common type of tremor. It is most noticeable when your hands are doing something and it usually affects both the right and left sides of the body equally. Essential tremors often lessen when your body is resting.

Unlike an essential tremor, a Parkinson's tremor is most obvious when the affected body part is resting and tends to be less noticeable with movement. It usually starts on one side of the body and may progress to the other side as Parkinson's develops.

How long will it take to get a confirmed diagnosis of Parkinson's?

The time it takes to get a confirmed diagnosis can vary from person to person. Some people may receive a diagnosis of Parkinson's quite quickly, but for others it may be a long process. This may be due to a number of things, including your medical history, your age and what symptoms you have.

Your specialist may wish to rule out other causes of your symptoms first and see how you respond to treatment. This may also take some time. And, as already mentioned, there is currently no definitive test for Parkinson's.

How you respond to treatment may help your specialist make a diagnosis. Keeping a diary or record of your symptoms may help the specialist.

Find out more: see our information sheet *Keeping a diary: people with Parkinson's*.

If you are waiting for a diagnosis and have any questions, you can call our helpline on **0808 800 0303**. You can also speak to others who are currently being diagnosed, or have already gone through a similar experience, through our online discussion forum at parkinsons.org.uk/forum

Is it possible to be misdiagnosed?

Because the symptoms of Parkinson's may be similar to other forms of parkinsonism, people can sometimes be misdiagnosed.

“ My GP was reluctant to refer me in the beginning. Eventually, he wrote a letter to a specialist. After four months, I had blood tests and an MRI scan. In all, it took two years to get the diagnosis. ”

Kris, diagnosed in 2004

It is difficult in the early stages to be certain what type of parkinsonism someone has. This is because your response to medication can be unclear as different forms of Parkinson's can respond to medication. But as time goes on, depending on what symptoms you have, and your response to Parkinson's medication, a specialist may be able to offer a more accurate diagnosis.

As there is currently no definitive test for Parkinson's, some experts prefer to use the term parkinsonism. They may only use Parkinson's once they have seen your condition following the typical pattern.

Will it be easier to diagnose Parkinson's more accurately in the future?

Researchers are currently exploring new and different ways to diagnose and monitor Parkinson's more accurately. These include looking at skin cells and blood samples to spot tiny but significant changes, and developing new and more sensitive imaging techniques, such as ultrasound.

Other research areas include whether some of the very early symptoms of Parkinson's, such as problems with sense of smell, can be detected using tests such as scratch and sniff tests and looking for other chemical markers of the condition in the blood.

It's difficult to say how long it will be before new and better tests for diagnosing Parkinson's become available, but research in this area is a major focus for Parkinson's UK.

Find out more: to keep up to date with the latest research, see the research pages on our website parkinsons.org.uk/researchnews

More information and support

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

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 also put you in touch with one of our local information and support workers, 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 also 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

You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.

Thank you

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

Dr Anette Schrag, Honorary Consultant Neurologist, Royal Free London and Reader in Clinical Neurology, Imperial College

Dr Duncan Forsyth, Consultant Geriatrician, Addenbrookes Hospital

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



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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
- Information and support worker
- Parkinson's UK local group or event
- Ordered from us directly
- Our website
- 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)

We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

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 **020 7932 1303** or visit our website at parkinsons.org.uk/support. Thank you.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday
10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website

at parkinsons.org.uk/publications

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this information sheet can be found in the Microsoft Word version at parkinsons.org.uk/publications

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