

Diagnosing Parkinson's

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

This information 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 on types of Parkinson's.

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

If you're concerned about symptoms you've been experiencing, you should visit your GP. If your GP suspects you have Parkinson's, clinical guidelines recommend they should refer you quickly to a specialist with experience in diagnosing the condition (and not try to treat you themselves).

It's 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?

Diagnosing Parkinson's can take some time as there are other conditions, such as essential tremor (see 'How long will it take to get a diagnosis of Parkinson's?'), with similar symptoms. There is also currently no definitive test for diagnosing Parkinson's.

Investigating symptoms

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

Parkinson's can cause many symptoms and these can vary from person to person.

Typical symptoms of Parkinson's include slowness of movement (bradykinesia), tremor, difficulty turning over in bed, fatigue and a tendency to have small handwriting.

Typical early symptoms include a reduced sense of smell, depression, anxiety, tiredness, disturbed sleep and constipation.

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's 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 and ask you about 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 for any of the typical signs of Parkinson's, the specialist will also look for signs that may suggest a different diagnosis.

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, and depending on the severity of your symptoms, 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 and scans to help diagnose Parkinson's

Your specialist may suggest you have a scan to help make a diagnosis. However, scans alone can't 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 they can be helpful in diagnosing other types 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 (muscles, for example) and organs. A certain type of SPECT scan is regularly used to help 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's 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, but in most cases it is due to 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, and how is it different to a Parkinson's tremor?

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

Essential tremor is the most common type of tremor. It's 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 diagnosis of Parkinson's?

The time it takes to get a 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 can 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 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 will give the specialist more information to guide their decision.

Find out more: see our information on monitoring your Parkinson's.

If you're 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, on our online forum at **forum.parkinsons.org.uk**

Is it possible to be misdiagnosed?

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

It's difficult in the early stages to be certain what type of parkinsonism someone has. However, 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's currently no definitive test for Parkinson's, some experts prefer to use the term parkinsonism when diagnosing people. They may only specifically diagnose Parkinson's if they see 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, sniffer dogs 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, visit 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 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:

Dr Duncan Forsyth, Geriatric Consultant, Addenbrookes Hospital

Professor Richard Walker, Consultant Physician and Honorary Professor of Ageing & International Health, North Tyneside General Hospital

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/ordering-resources** 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**

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Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)
-

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

- Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions

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

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated November 2018. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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