

DIAGNOSING PARKINSON'S

About Parkinson's

Find out more about how Parkinson's is diagnosed and learn about the other types of parkinsonism.



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DIAGNOSING PARKINSON'S

Research suggests that Parkinson's tends to develop gradually. It may be many months, even years, before the symptoms become obvious enough for someone to visit their GP.

This information looks at 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 a condition when someone experiences slowness of movement and at least one other of these symptoms:

- tremor
- stiffness
- balance problems

Idiopathic Parkinson's

The most common form of parkinsonism is idiopathic Parkinson's, or Parkinson's.

Idiopathic means the cause is unknown.

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

Common symptoms of Parkinson's include:

- slowness of movement (bradykinesia)
- tremor
- stiffness
- fatigue
- having smaller handwriting

Typical early symptoms which you might notice include:

- a reduced sense of smell
- depression
- anxiety
- tiredness
- problems with sleep
- constipation

Everyone's experience is different and not everyone will experience all of these symptoms.

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

If you're worried about symptoms you've been experiencing, you should visit your GP.

Before your appointment, think about your symptoms. For example, do your symptoms get worse at certain times? How do they affect your day-to-day life? You may find it helpful to write these down.

You may also want to think about anything else you think your GP needs to know, such as any medication you're taking, or questions you'd like to ask. This can help if you're feeling anxious or worried and to get the most out of your appointment.

During the appointment your GP will ask you questions about your mental and physical health. Try to be as honest as possible. Give them as much detail as you can about how you're feeling and what your symptoms are.

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.

How is Parkinson's diagnosed?

It's not always easy to diagnose Parkinson's. There's currently no single or definitive test that can diagnose the condition and there are other

conditions that have similar symptoms.

The risk of developing Parkinson's increases with age. Most people who get Parkinson's are aged 50 or over, but younger people can get it too.

Before your appointment with a specialist, you may find it helpful to keep a diary or record of your symptoms to help you explain what's been happening. 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.

It may be helpful to take someone with you for support when you see a specialist. If a healthcare professional says something you don't understand, don't be afraid to ask them to explain what they mean.

At your appointment

Your specialist will take a detailed medical history and examine you.

You may be asked to:

- write or draw something – to see if your writing is small or gradually fades
- walk – to see whether your arms naturally swing while you move or your stride length gets shorter or slower
- speak – to see if your voice is soft or very quiet

Your specialist will also look at and ask you:

- if your face has a 'masked' look or if you have problems with facial expressions. This can be a symptom of Parkinson's
- if you experience a tremor, any stiffness (rigidity) or slowness of movement

As well as looking for any of the typical signs of Parkinson's, the specialist will also look for signs that may mean you don't have Parkinson's, for example:

• **Essential tremor**

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

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

A Parkinson's tremor is most obvious when you're resting and tends to be less noticeable when you're moving. It usually starts on one side of the body and may progress to the other side as Parkinson's develops.

• **Dementia with Lewy bodies**

Dementia with Lewy bodies shares some symptoms with Parkinson's, such as rigidity, thinking more slowly and anxiety or depression.

If you've noticed changes in your thinking and memory, you should talk to your GP. It's important to act early as there may be treatments that you can benefit from and things that you can do to improve your symptoms.

Find out more: see our information on thinking and memory changes.

Response to Parkinson's drugs

After examining you, and depending on how much your symptoms affect you, your specialist may suggest you start taking 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.

But some people with other forms of parkinsonism will also respond well to these drugs. So your specialist will review your diagnosis regularly depending on how your symptoms develop.

Other medical tests and scans to help diagnose Parkinson's

Your specialist may suggest you have a scan to help make a diagnosis. But scans alone can't definitely diagnose Parkinson's, so they're not always used.

MRI or CT scans

An MRI or CT scan looks at the structure of your brain. These scans can't diagnose Parkinson's, but they can be helpful in diagnosing other types of parkinsonism. Read more about these on page 10.

SPECT or DaTSCAN

These are scans that can tell your specialist how different areas of your brain are working. SPECT is a type of imaging test that shows how blood flows to tissues (muscles, for example) and organs.

A dopamine transporter scan, known as a DaTSCAN, is a type of SPECT scan that can tell your specialist if you've lost dopamine-producing brain cells. It's the loss of these cells that causes Parkinson's to develop.

But losing dopamine-producing brain cells may also be a sign of some other, rarer neurological conditions. So an abnormal DaTSCAN result alone can't definitely prove you have Parkinson's.

A normal DaTSCAN can be helpful in showing that a person's symptoms, particularly tremor, are not caused by Parkinson's. But your symptoms may be due to another condition, such as essential tremor. For more information about essential

tremor, please see page 5 of this booklet.

Other specialist tests

Your specialist may also request other specialist tests. These include:

- a metaiodobenzylguanidine (MIBG) scan of your heart
- a lumbar puncture, which tests the spinal fluid that surrounds your brain
- electrical recording (EMG) of the urethral or anal sphincter, to check the health of the muscles and nerves that control them. Your anal sphincter is the muscle that controls your back passage, while your urethral sphincter muscle controls the tube that takes urine (pee) out of your body when you pee
- autonomic function tests (AFTs) to record your pulse and blood pressure

Sometimes a test or a series of tests can help strengthen the case for a specific diagnosis, or rule out a condition. But this is only after your specialist has considered your symptoms and

the results from your medical examination.

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

The time it takes to get a diagnosis is different for everyone.

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 or see how you respond to treatment. Keeping a diary or record of your symptoms will give your specialist more information to guide their decision.

Waiting for a diagnosis can be stressful. You may feel anxious or frustrated that someone can't tell you what's wrong. Other people may feel angry that this is happening

at all or worried about what a diagnosis might mean for the future. The uncertainty can feel overwhelming.

These feelings are all normal and there is no right or wrong way to deal with them. For some people, talking with friends or family can help. You can also speak to others who are currently being diagnosed, or have already gone through a similar experience, on our online forum at parkinsons.org.uk/forum

You may want to look for more information about Parkinson's while you wait for a diagnosis, to help you feel more informed. You can read more about living with Parkinson's on our website at parkinsons.org.uk/information-and-support. All of our information is checked by experts and other people with Parkinson's, so you know it's information you can trust.

How might I feel when I'm diagnosed?

Being diagnosed with Parkinson's can be a very emotional experience. Some people feel shocked or confused – others feel angry or anxious. Some people even feel relieved to have an explanation for their symptoms.

If you're waiting for a diagnosis or have just been diagnosed and have any questions, you can call our helpline on **0808 800 0303** or email hello@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.

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 which could be linked to Parkinson's. They are also 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 or on the skin.

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. Better ways of diagnosing and monitoring Parkinson's could also help make research studies more efficient, leading to better treatments in the future.

Learn more about our Parkinson's research, including how you get can involved, on our website at parkinsons.org.uk/research

Other types of parkinsonism

Parkinsonism is an umbrella term used to cover a range of conditions that share similar symptoms to Parkinson's itself.

Vascular parkinsonism

Vascular parkinsonism affects people whose blood supply to their brain is limited - if you have had a mild stroke, for example. A stroke usually happens suddenly, so vascular parkinsonism symptoms can develop quickly, but not always.

The symptoms of vascular parkinsonism include slowness of movement and stiffness. But vascular parkinsonism is also known as 'lower body parkinsonism' because it usually affects your mobility.

People can have problems when walking, which means they can be unsteady on their feet, walk with short shuffling steps, or have balance problems.

Vascular parkinsonism can also cause bladder problems, communication problems and thinking and memory problems.

How is vascular parkinsonism managed?

Your specialist will normally suggest you start taking Parkinson's medication to see how your symptoms respond.

For most people, the symptoms of vascular parkinsonism usually don't improve with medication. More research is needed to understand why this is the case, or what the ideal dose may be to manage symptoms.

There are other ways vascular parkinsonism can be managed:

- Physiotherapy and occupational therapy - a physiotherapist can show you ways to help improve your confidence and reduce any fear of falling. They can also teach you techniques to help you get down safely on to the floor and up again if you do fall.

- An occupational therapist can show you ways to help reduce your risk of falling. To help with this, they might ask you to keep a falls diary to record when, where and how you fall.

Find out more: see our information on physiotherapy and Parkinson's, and occupational therapy and Parkinson's.

- Lifestyle changes - if you have experienced a stroke in the past, your doctor will advise you to make changes to your lifestyle. This can help lower your risk of having another stroke. These may include stopping smoking, eating a low-fat diet, and being physically active.

Drug-induced parkinsonism

The symptoms of drug-induced parkinsonism include slowness of movement,

tremor, stiffness and difficulty walking.

Symptoms usually appear quickly, but tend to stay the same. It's rare that symptoms get worse, like in Parkinson's.

Neuroleptic drugs (used to treat schizophrenia and other severe mental health conditions) are the biggest cause of drug-induced parkinsonism. They block the action of the chemical dopamine in the brain.

Most people will recover, often within days or weeks, of stopping taking the drug that has caused the symptoms.

Multiple system atrophy (MSA)

MSA is a rare condition that affects the nervous system and causes damage to nerve cells in the brain.

Like Parkinson's, it can cause stiffness and slowness of movement in the early stages of the condition. But people can also develop symptoms that are more unusual in the

early stages of Parkinson's, such as bladder problems, dizziness, and problems with coordination, balance and speech.

Symptoms tend to develop and progress rapidly.

Progressive supranuclear palsy (PSP)

PSP is sometimes called Steele-Richardson-Olszewski syndrome. It's caused by brain cells becoming damaged over time.

Symptoms of PSP can include stiffness and problems with balance and mobility, speech, swallowing and vision.

There is no medication to treat PSP specifically, but you may find Parkinson's drugs, such as levodopa or amantadine, can help with some symptoms.

Normal pressure hydrocephalus (NPH)

Hydrocephalus is a build-up of fluid in the brain. NPH tends to affect older people.

The main symptoms of NPH are difficulty walking, bladder

problems and thinking and memory changes.

Sometimes the condition can be treated by surgery. A thin tube, called a 'shunt', is inserted in your brain. The extra spinal fluid can then flow through the shunt to another part of your body and is absorbed into your blood.

Corticobasal degeneration (CBD)

CBD causes problems with movement, speech, memory and swallowing. It's caused when brain cells become damaged or die over time.

There's no cure or specific treatment for CBD. But symptoms can be managed with a range of treatments including medication, physiotherapy, occupational therapy and speech and language therapy.

Wilson's disease

Wilson's disease is a rare, inherited disorder where your skin and muscles contain too much copper.

It can cause tremor, problems with coordination, balance and speech, and dystonia, which can cause painful muscle spasms.

More information and support

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis.
- help people to manage their medication, so they get the best results and fewer side effects.
- make referrals to other professionals such as speech and language therapists and physiotherapists.

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

You can read our most up-to-date information at parkinsons.org.uk.

You can order printed information by calling **0330 124 3250** or visiting parkinsons.org.uk/orderingresources

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's. They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on **0808 800 0303** or email hello@parkinsons.org.uk

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to parkinsons.org.uk/localgroups or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit parkinsons.org.uk/forum

Thank you

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

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

Feedback

If you have any comments or feedback about our information, please call

0800 138 6593, email feedback@parkinsons.org.uk, or write to us at Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at healthcontent@parkinsons.org.uk or visit our website.

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 Care team on **0800 138 6593** or visit our website at parkinsons.org.uk/donate

Thank you.

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Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
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