

Does Parkinson's run in families?

If you or one of your relatives has Parkinson's, you may want to know if the condition can be passed down through families.

This information answers your questions about whether Parkinson's can be inherited, and if there is any way to test for it.

Key points:

- It's very rare for Parkinson's to run in families.
- The vast majority of people have what is called 'idiopathic Parkinson's', meaning that there's no known cause.
- However, for a small minority of people with Parkinson's, there is a genetic link.

How do genes work?

We all have two copies of 23,000 genes. Together, these genes (our 'genome') act as a blueprint that makes us who we are. Subtle variations make every person's genome unique, and make us all different. We get half our genes from our mother and half from our father.

Sometimes, a gene has a difference (a 'variant' or 'mutation') that means the protein it produces doesn't work as well as it should. This can increase someone's risk of getting a particular illness.

It's very rare for a health condition to be caused by a change in a single gene. Like most of our characteristics, our health is generally the result of a mixture of different genes with other factors such as diet and exercise.

How many cases of Parkinson's are caused by genetics?

Parkinson's caused by genetic factors is extremely rare, but does happen sometimes:

- Some people with Parkinson's carry a very rare change in a gene that causes the condition directly. People diagnosed with Parkinson's at a younger age are more likely to have a genetic link. Changes have been identified in genes including alpha synuclein, parkin, PINK1, DJ-1, ATP13A2, PLA2G6, FBXO7 and VPS35, and often cause symptoms to develop at a young age.
- A change in the LRRK2 gene known as G2019S is probably the most common genetic variant linked to Parkinson's. In the UK, around one in 100 people with Parkinson's carry it. It's more common in North African and Jewish populations. People who carry this variant may develop the condition later in life and have around a 70% chance of being diagnosed by the age of 80.
- As well as single genetic changes that directly cause the condition, we now know that there are also changes that increase risk. The most common of these is having a variant in the GBA gene. These changes are more common but their effects are more subtle. Carrying one of them means you are more likely to develop Parkinson's but often only very slightly.

If I have Parkinson's, will my children develop it?

It's very rare for people to pass Parkinson's on to their children.

Even if your Parkinson's is in part caused by the genetic factors mentioned above, it's far from certain that you would pass the relevant genes on to your children.

However, there are some cases where it does seem that Parkinson's has been passed from one generation to the next.

Can I have my genes tested to find out if I'm at higher risk?

In some cases, where there's a strong indication that Parkinson's may have genetic causes, it may be possible to have genetic testing to understand why the condition has happened.

It may also be possible for family members to have a predictive test, again where there's a strong indication that Parkinson's runs in their family.

However, these tests are unlikely to influence the type of care a person with Parkinson's receives (although that may change in the future). In many cases, they're also unlikely to give a definitive answer on whether Parkinson's will definitely be passed on. They are not available in all areas of the UK.

Speak to your GP, specialist or Parkinson's nurse to see if testing would be beneficial for you and your family, and if it's available in your area.

Why is there so much interest in Parkinson's genes?

The number of people affected by genetic forms of Parkinson's is very low. But understanding the role genes play in a person's condition might shed light on what causes Parkinson's and potential new treatments.

There are many researchers in the UK who are studying the genetics of Parkinson's. They may be looking for people with Parkinson's to take part in their studies.

Find out more about taking part at parkinsons.org.uk/takepartresearch

Glossary

Alpha-synuclein gene

The alpha-synuclein gene provides instructions for making a small protein called alpha-synuclein. This protein is found throughout the body, including in the brain. Research suggests that changes in this gene may play a role in the development of Parkinson's.

Carrier

We all carry two copies of most genes. A 'carrier' (or genetic carrier) is a person who has inherited a change in one copy of the gene, but does not have the symptoms of the genetic health condition related to this change.

Genetic counselling

Advice and support given to parents about the risks of their child developing conditions with a genetic cause.

Genetic medicine

The branch of medicine that involves the diagnosis and management of hereditary disorders.

Genetic risk factor

A risk factor is anything that can increase your chance of developing a condition. A genetic risk factor comes from your genes.

Neurogenetics

The study of the role of genes in the development and function of the nervous system (brain and spinal cord).

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.

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:

Tom Foltnyie, Consultant Neurologist in Movement Disorders, National Hospital for Neurology and Neurosurgery.

Ronald Pearce, Consultant Neurologist and Honorary Senior Lecturer, Imperial College, Charing Cross 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**

Does Parkinson's run in families? (PKFS86/2019)

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 February 2019. 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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