

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

Most people have what is called 'idiopathic Parkinson's', meaning that there is no known cause and no clear genetic cause. Research is being carried out on the role of genes in idiopathic Parkinson's, and whether there are any genes that increase your risk of developing the condition but do not have a major effect on your family's risk of developing it.

It is estimated that only a very small number of people may have an increased risk of Parkinson's linked to their genes. So, it's very rare for people to pass on Parkinson's to their children.

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

It is rare for people to pass Parkinson's on to their children. However, there are cases where it does seem that Parkinson's has been passed from one generation to the next. Where this happens there are specific genetic factors that appear to play a part, such as changes in the alpha-synuclein gene.

We still don't know exactly what causes Parkinson's. In addition to specific genetic factors that cause a condition, there are also genetic risk factors that do not mean you will definitely get the condition, but may slightly increase your risk of developing it. Just as people who have inherited high cholesterol or blood pressure are at risk of heart problems, our environment and lifestyle may play a big part in deciding who actually goes on to develop certain conditions.

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

In some cases it's possible for family members of people with Parkinson's to have a predictive test to see if they carry a Parkinson's genetic risk factor. This will usually happen with support and counselling from the local NHS medical genetics service.

Some private companies offer genetic testing, but the information provided is often limited and the companies may not provide counselling or advice.

If you have already been diagnosed with Parkinson's, genetic testing can help you and your doctor to understand why the condition has happened. At the moment, having a positive genetic test result will not change your treatment, but this might change in the future.

Having a genetic test may be particularly informative if you have a strong family history of Parkinson's or if you have early-onset Parkinson's (before the age of 40). If your genetic test for Parkinson's is positive, you and your family will be offered detailed genetic counselling and advice.

If you are worried about the risk of developing Parkinson's in your family, speak to your GP, specialist or Parkinson's nurse. They may refer you for testing with a doctor or counsellor who specialises in genetic medicine or neurogenetics.

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. Read on for details of our Research Support Network and how to get involved in research.

Find out more: visit parkinsons.org.uk/researchstudies

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 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 symptoms of the genetic disease 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.

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:

Professor Huw Morris, Consultant Neurologist and Professor of Clinical Neuroscience at the Royal Free Hospital, National Hospital for Neurology and Neurosurgery, and UCL Institute of Neurology

Dr Alastair Noyce, Parkinson's UK Doctoral Research Fellow at UCL Institute of Neurology and Specialist Registrar in Neurology in London

Professor John Hardy, Chair in the Department of Neuroscience at UCL

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? (FS86/2018)

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 June 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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