Inherited Parkinson’s and genetic testing

If you or someone in your family has Parkinson’s, you may want to know whether it can be inherited, or passed down through families.

This information sheet looks at whether Parkinson’s can be inherited, and whether there is any way to test for the condition.

Does Parkinson’s run in families?
Scientists estimate that around 5% of cases of Parkinson’s (ie five in every 100 people with Parkinson’s) may be inherited. The remaining 95% of people with Parkinson’s have what’s called ‘idiopathic Parkinson’s’ (meaning that there is no known cause). Current research is looking into the role genes play in people developing this type of Parkinson’s.

Will my children develop Parkinson’s?
It is very rare for people to pass Parkinson’s on to their children. There are cases where it does seem that Parkinson’s has been passed on from one generation to the next. When this happens there are certain genes that appear to play a part.

We still don’t know exactly what causes Parkinson’s. Researchers have found there are changes in certain genes that are linked to a higher risk of getting Parkinson’s. But even if you have these gene changes, the chances of you going on to develop Parkinson’s are still very low. Having one of these gene changes simply increases your risk of developing the condition. Just as people who have inherited high cholesterol or blood pressure are at risk of heart problems, environment and lifestyle play a big part in deciding who actually goes on to develop certain conditions.
Can I have my genes tested to find out whether I’m at higher risk?

Genetic testing is not usually available on the NHS. Testing is sometimes offered for people thought to be at a higher risk, for example, if they have a strong family history of Parkinson’s or early onset of the condition (before the age of 40). If they have a positive genetic test, then the rest of the family may also be offered a predictive test.

These tests are only carried out after counselling and advice. Knowing there is an increased risk of developing Parkinson’s may cause unnecessary worry in people who may never go on to develop it.

If you are worried about the genetic risk of developing Parkinson’s, then speak to your GP, specialist or Parkinson’s nurse (if you have one). They may suggest referral to a doctor or counsellor who specialises in genetic medicine.

More information and support

Our Research Support Network brings together people driven to help find a cure and better treatments for Parkinson’s. Through our network, anyone can get involved in research and raise funds and awareness for Parkinson’s research.

If you would like to know more about how you can get involved in supporting research, contact us at rsn@parkinsons.org.uk or on 020 7963 9376.

We list UK clinical trials on our website parkinsons.org.uk/research

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 act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson’s nurses may not be available in every area, but your GP or specialist can give you more details on local services.

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

Our helpline can also put you in touch with one of our local information and support workers, who provide one-to-one information and support to anyone affected by Parkinson’s. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at parkinsons.org.uk/localtoyou. You can find details of our local groups and your nearest meeting at parkinsons.org.uk/localgroups. You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.
Thank you to everyone who contributed to and reviewed this information sheet:

Professor Huw Morris, Senior Lecturer, Department of Neurology, University Hospital of Wales

Choo Wright, Parkinson’s Disease Nurse Specialist, First Community Health and Care, Redhill

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

Inherited Parkinson’s and genetic testing

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 Resources and Diversity, 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

☐ Parkinson’s UK local group or event

☐ Our website

☐ Information and support worker

☐ Ordered from us directly

☐ 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
How to order our resources
01473 212 115
resources@parkinsons.org.uk
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

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.

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? ...........................................................................................................................................................................................
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Were you looking for any information that wasn’t covered? ...........................................................................................................................................
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Do you have any other comments?
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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) ...........................................................................................................................................

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