

Information about screening tests for Lynch syndrome

Other formats

If you need this information in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, please contact the PALS desk on 01271 314090 or at ndht.pals@nhs.net.

How common is colon cancer?

Approximately 1 in 20 people in the UK will develop cancer of the colon or rectum during their lifetime. It is slightly more common in men. Most colon cancer is seen in people over 50, and is commonest over 65.

What causes colon cancer? Is it inherited?

Most colon cancers are not inherited, but arise "out of the blue" in a family. There is no single cause; it is usually the result of a mixture of adverse risk factors. These include external factors, such as diet, alcohol, exercise, obesity etc, as well as mild genetic influences. Any person who has an affected relative will have a small increased risk themselves because they will probably share some of these factors, but the risk is usually not high.

How common is inherited colon cancer?

It is not very common. Only 10-15% of colon cancer has a significant genetic basis. A specific condition called Lynch syndrome (also known as HNPCC, Hereditary Non Polyposis Colon Cancer) is the commonest cause of inherited colon cancer (it is believed to account for around 2-3% of all colon cancers).

Why am I being offered a test if it is so rare?

It is important to know if a person has Lynch syndrome. There may be implications for your treatment and future health: Lynch syndrome cancers sometimes respond differently to chemotherapy so treatment may be slightly different, and there may be an increased risk of a new cancer in the future, in which case extra screening or other measures would be recommended. There would also be important implications for family members, who may have an increased cancer risk, and who may benefit from cancer screening.

This is why the National Institute for Health & Care Excellence (NICE) now recommends that all people with a new diagnosis of colorectal cancer should be offered some screening tests for Lynch syndrome.

How are these tests done?

These tests can be done on a tiny sample of the tumour tissue that is removed in the usual course of an operation.

What will the results mean?

If these tests are negative, it would make Lynch syndrome even more unlikely.

If the tests are positive, it would increase the likelihood of Lynch syndrome and more detailed tests would be recommended.

What happens if my tests are positive?

If your tests are positive, we would usually refer you to our colleagues in the Clinic Genetics Department to consider more detailed and specific testing for Lynch syndrome. This usually involves a simple blood sample. The results can take several weeks.

It is important to be aware that if it turns out that you do have Lynch syndrome, this may have implications for your own health in the future. For example, people with Lynch syndrome have an increased risk of a variety of cancers, not just colorectal. These include cancer of the stomach, pancreas and bile duct, cancer of the womb or ovary in women, and prostate cancer in men.

If you are found to have a genetic misprint that causes Lynch syndrome, there is a 50% chance that your close relatives have the same genetic misprint. Although the risk of developing a cancer will depend on which gene is involved and on whether they are male or female. Please note that Lynch syndrome does **not** cause cancer in childhood so any testing in the family would only apply to adults.

Please remember:

Most colorectal cancers diagnosed over 50 years of age will **not** have a strong genetic cause, so the most likely outcome of these tests is a **normal result**.

It is important to understand that the tests being offered to you now are screening tests rather than diagnostic tests. By this we mean that the results indicate whether you are at high or low risk of Lynch syndrome. They cannot rule it out, nor can they prove that you have Lynch syndrome. However, if your tests are negative, you would be reassured that Lynch syndrome is very unlikely.

Do I have to have a test?

No. Tests will only be done with your full consent. If you have any questions or would like to have a more detailed talk about these tests, please ask your consultant.

Is it important to know about other cancers in the family?

Yes, but we need to remember that cancer is very common; one in three people will get cancer at some point, so it is quite possible there are other people with cancer in the family just by chance.

However, certain patterns of cancer in a family 'ring alarm bells' and may indicate a genetic form of cancer. For example:

- Three or more people in the family with colon cancer.
- You or a relative diagnosed with colon cancer before the age of 50 years.
- Certain other cancers; in particular cancer of the womb (uterus, endometrium) or ovary in women, stomach, bladder or prostate – particularly if diagnosed at a young age.
- Multiple polyps in your bowel or your relatives'.

Should my relatives have any colon screening?

No. Not unless your tests are positive or it is recommended by your doctors.

If they have to have screening, what would this involve?

This is usually done by a procedure called colonoscopy, which you may have had yourself. A narrow flexible tube is passed into the back passage; mild sedation can be used but general anaesthetic is not usually necessary. The lining of the colon can then be viewed directly. Many colon cancers develop from harmless growths in the colon called "polyps" or "adenomas". If a polyp is found, it can be removed during the colonoscopy to prevent it from developing into a cancer. Any procedure carries a small risk, and this needs to be taken into account when deciding who is likely to benefit from a colonoscopy.

Is there anything else my relatives should do to reduce their risk?

Yes. There is evidence that diet is important in colon cancer risk. It is important to eat plenty of fresh vegetables and fruit and to reduce the amount of animal fat, particularly red and processed meat (a diet high in processed food, fat or red meat is associated with a higher risk). Being overweight is a significant risk factor and so is smoking and excessive alcohol. Regular exercise lowers risk and helps to control weight.

What are the symptoms they should look out for?

Bleeding from the back passage or a change of bowel habit (diarrhoea or constipation persisting for more than a couple of weeks) should be reported to your doctor. Although these symptoms usually have an innocent cause, they may indicate an early colon cancer. Leaflets about this are available so if you have not been given one of these, please ask us or your doctor.

How will I receive my results?

The results will take several weeks and you will receive the results via your consultant. If you have any questions about your result, please contact the Colorectal Nurses on 01271 322464, Monday – Friday, 8.30am – 4.30pm.

Author: Dr Carole Brewer, Consultant in Clinical Genetics, Royal Devon and Exeter NHS Foundation Trust

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern call 01271 314090 or email ndht.pals@nhs.net. You can also visit the PALS and Information Centre in person at North Devon District Hospital, Barnstaple.

Have your say

Northern Devon Healthcare NHS Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

'Care Opinion' comments forms are on all wards or online at www.careopinion.org.uk.

Northern Devon Healthcare NHS Trust
Raleigh Park, Barnstaple
Devon EX31 4JB
Tel. 01271 322577
www.northdevonhealth.nhs.uk

© Northern Devon Healthcare NHS Trust
This leaflet was designed by the Communications Department.
Tel: 01271 313970 / email: ndht.contactus@nhs.net