



Lynch syndrome

An inherited condition that raises the risk of bowel and other cancers

PE-GIC-31

Lynch syndrome is an inherited change in a gene that normally repairs DNA. It increases the risk of bowel, womb and some other cancers, often at a younger age than usual. Regular colonoscopy, risk-reducing options and testing of relatives make a real difference: many cancers can be prevented or found early.

What is it?

When cells divide, 'mismatch repair' genes correct errors in copying DNA. In Lynch syndrome, one copy of one of these genes (MLH1, MSH2, MSH6 or PMS2, or a deletion in EPCAM that switches off MSH2) carries a change (variant) that stops it working properly, so errors build up and cancers can develop earlier than usual.

Lynch syndrome runs in families. Each child of a person with Lynch syndrome has a 1 in 2 chance of inheriting it, whether a son or a daughter. Not everyone who carries it develops cancer.

Which cancers?

The level of risk depends on which gene is affected: MLH1 and MSH2 generally carry the highest risks, and MSH6 and PMS2 lower ones. Cancers linked to Lynch syndrome include:

- Bowel (colorectal) cancer
- Womb (endometrial) cancer, which in women can be as common as, or more common than, bowel cancer
- Ovarian cancer
- Stomach and small bowel cancer
- Less commonly, cancers of the urinary tract, prostate, pancreas, bile ducts and brain, and some skin growths

How is it diagnosed?

- Bowel and womb cancers are often tested in the laboratory for faulty mismatch repair; an abnormal result can lead to genetic testing
- A blood or saliva genetic test confirms the gene change
- Testing may be offered because of a strong family history of related cancers, especially at younger ages
- Once the gene change is known in a family, relatives can be tested for that specific change

Bowel surveillance

Regular colonoscopy finds and removes polyps before they become cancer, and detects cancers early. Current British and European guidance recommends:

- Colonoscopy every 2 years
- Starting at about age 25 for MLH1, MSH2 and EPCAM carriers, and about age 35 for MSH6 and PMS2 carriers
- A high-quality examination with excellent bowel preparation, ideally in a specialist unit
- Continuing until about age 75, then reviewed individually

Some guidelines, including American ones, recommend starting earlier or checking more often. Your team will set your schedule according to your gene and family history.

Other ways to lower your risk

- Aspirin: studies suggest that daily aspirin may lower bowel cancer risk in Lynch syndrome, but it is not given routinely because of the risk of bleeding. Do not start aspirin on your own; your doctor will discuss it with you if it may be suitable
- Gynaecological care: women should report warning symptoms promptly. Removing the womb, tubes and ovaries once a family is complete, often from around age 35 to 40 depending on the gene (for some genes, such as PMS2, the ovaries may not need to be removed), prevents most of these cancers. A gynaecologist will discuss timing, early menopause and hormone replacement
- Stomach: a test for *H. pylori*, with treatment if positive, is recommended. Some people are offered gastroscopy, depending on the gene and family history
- Report symptoms early rather than waiting for your next check

- Do not smoke, stay active and keep a healthy weight

Your family

Your brothers, sisters and children each have a 1 in 2 chance of carrying the same gene change, and one of your parents probably carries it too. Telling them allows 'cascade' testing, usually from age 18. Carriers can start surveillance; those who do not carry it have general-population risk and need no extra checks for Lynch syndrome.

Genetic counselling before and after testing helps you understand the results, share them with your family, and consider the options for future pregnancies.

Get urgent medical care if you have

- Blood in the stool, black stools, or a change in bowel habit lasting more than a few weeks
- Bleeding between periods, after intercourse or after the menopause
- Blood in the urine
- Unexplained weight loss, persistent abdominal pain or swelling, or difficulty swallowing

Common questions

Does Lynch syndrome mean I will get cancer?

No. It raises the risk, but many carriers never develop cancer, and surveillance and risk-reducing steps prevent many cancers or find them at a curable stage.

Should my children be tested now?

Bowel surveillance does not start in childhood, so testing is usually offered from age 18, when a young adult can make an informed choice. An exception is when both parents carry a Lynch gene change, which is more likely if they are related. A child can then inherit two changes, causing a rare condition with cancers in childhood, so tell your genetics team: these children need assessment early.

Do I need colonoscopy more often than every 2 years?

Under British and European guidance, not routinely, if your examinations are complete and of high quality. Your doctor may advise a shorter interval if polyps are found or the preparation was poor.

Can diet prevent cancer in Lynch syndrome?

No diet removes the risk. A healthy lifestyle helps general health, but regular colonoscopy, gynaecological care and the other steps your team recommends are what make the difference.

This leaflet is general information and does not replace advice from your own doctor. Version 1.0, October 2026. Next review October 2028.

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