



Lynch syndrome Questions and Answers

Information for patients and families



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Contents

1. If I have Lynch syndrome, will I get cancer?	4
2. How can I reduce my risk of cancer?	6
3. Will I have to get regular colonoscopies?	7
4. How does Lynch syndrome affect my family?	8
5. Can it skip a generation?	9
6. Who should I tell if I have Lynch syndrome?	9
7. Where can I get more support?	10
Further information	11
Acknowledgements	13

1. If I have Lynch syndrome, will I get cancer?

Not everyone with Lynch syndrome will develop cancer, but you have an increased risk compared to the general population. People with Lynch syndrome have an increased risk of developing some types of cancer, such as:

- bowel (colorectal) cancer (Diagram 1 shows large intestine and colon)
- endometrial or uterine cancer – affects the lining of the womb (endometrium) (Diagram 2 shows parts of the female anatomy)
- ovarian cancer (Diagram 3 shows the female reproductive system)

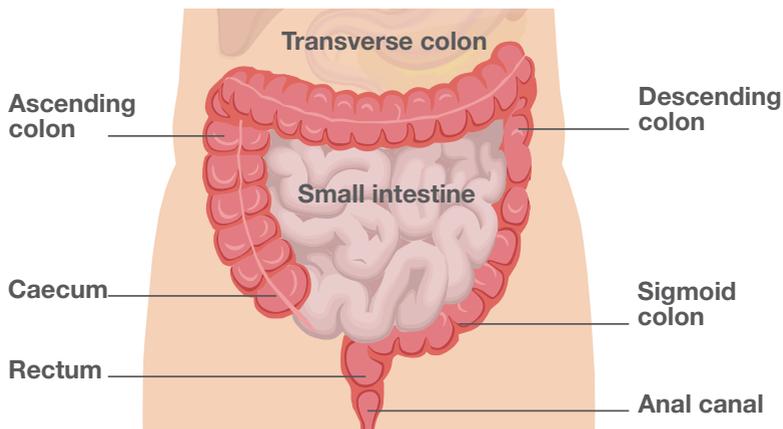


Diagram 1: Large intestine and colon

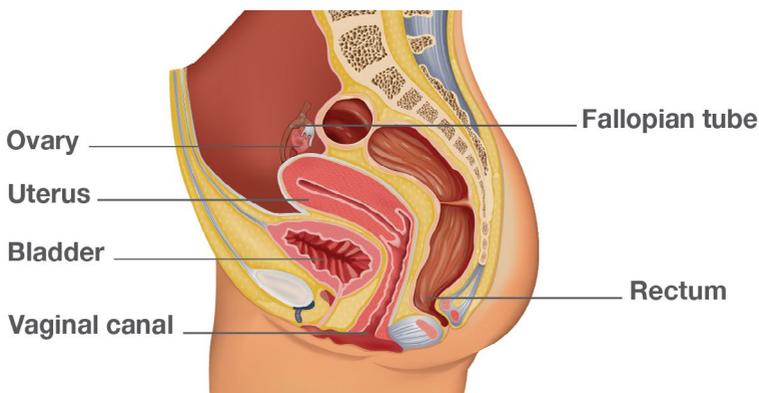


Diagram 2: Female anatomy

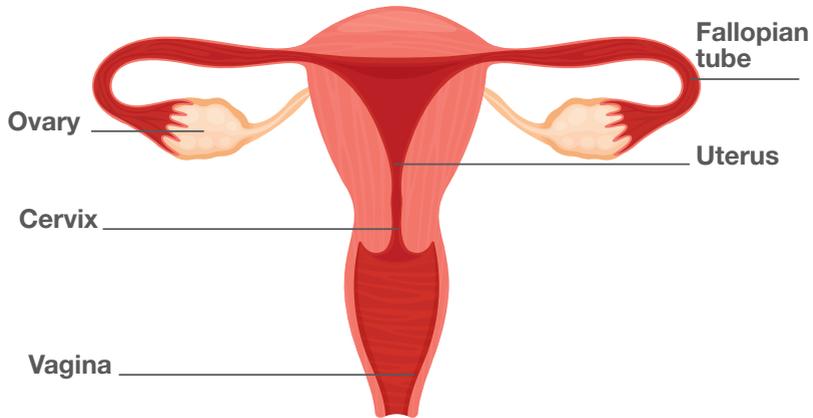


Diagram 3: Female reproductive system

Your risk of developing cancer depends on which gene is affected, your age and being a man or a woman. Your doctor will discuss your individual risk with you.

More information



To find out about your risk of developing cancer in Lynch syndrome check out the Prospective Lynch syndrome database (PLSD) on plsd.eu or **scan the QR code**.

It has a tool to help you calculate your risk for cancer by age, gene affected and gender.

There are lots of graphs and numbers involved in calculating your risk. You may need help from your healthcare professional. You can also ask a member of your healthcare team about your risk.

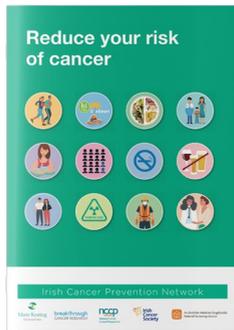
2. How can I reduce my risk of cancer?

Your risk of getting cancer is affected by lots of things. This includes things you can change, like your lifestyle habits, and things you can't change, like your age and your genes.

We can all reduce our risk of cancer by:

- trying to live a healthy lifestyle
- maintaining a healthy body weight
- eating a balanced diet with plenty of fibre and less red and processed meat such as chorizo, bacon or salami
- limiting our alcohol intake
- avoiding smoking
- exercising

More information



To find out about reducing your risk of developing cancer

visit **hse.ie**
and search: 'cancer prevention'

or **scan the QR code**

People with Lynch syndrome are invited for regular colonoscopies (about every two years).

Getting colonoscopies can help to reduce your risk of cancer, because small growths (called 'polyps') that might develop into cancer in the future can be found and removed from the bowel.

Regular colonoscopies can also help to find bowel cancer early, before it has caused any symptoms.

Taking aspirin can also reduce the risk of bowel cancer, **but** it may not be suitable for everyone. Speak to your doctor to see if it is an option for you.

You may also be offered one-off testing for *Helicobacter pylori*.

Helicobacter pylori is bacteria that can be found in your stomach. It can increase your risk of stomach ulcers and cancer. Your doctor can arrange a test, which can be done by stool (poo) sampling or a breath test. You can treat it with antibiotics. This can help reduce your risk of stomach cancer.

3. Will I have to get regular colonoscopies?

Individuals with Lynch syndrome are encouraged to get regular colonoscopies. They help to check for bowel cancer.

A colonoscopy is a test to look at your bowel using a small camera. Some people with Lynch syndrome start to get colonoscopies at 25 or 35 years old and they get a colonoscopy every 2 years. Your healthcare providers will decide when to start getting colonoscopies. This will depend on your genes and medical history.

Cancer can happen at any time, including between regular colonoscopies. If you develop symptoms of cancer, contact your doctor without delay, even if you recently had a colonoscopy or are due for one soon.

More information



To view the signs of
early cancer
scan the QR code



To view the signs of
early bowel cancer
scan the QR code

It is important to know the signs and symptoms of cancer, especially bowel, endometrial and ovarian cancer.

If you develop any of these signs and symptoms, or anything unusual for you that is not getting better, contact your doctor without delay.

4. How does Lynch syndrome affect my family?

Genes are inherited in pairs. You inherit one from your mother and one from your father. If someone has Lynch syndrome, one copy of a mismatch repair (MMR) gene is altered and is not working properly. A mismatch gene is a gene involved in making repairs to errors in DNA. If a parent has Lynch syndrome, they can pass the affected gene on to their children. This means that each of their children have a 1 in 2 (50%) chance of also having Lynch syndrome.

Knowing this information means you can take steps to reduce your risk of developing cancer. Ask your healthcare provider about where you can get support to talk to your family.

5. Can it skip a generation?

No. Lynch syndrome does not skip generations. But if you have Lynch syndrome that does not mean all of your children will have Lynch syndrome. If one parent has Lynch syndrome there is a 1 in 2 chance that each child will also have Lynch syndrome.

6. Who should I tell if I have Lynch syndrome?

It is important to tell your close relatives — parents, brothers and sisters and children — about your diagnosis, as they have a 1 in 2 chance of having Lynch syndrome. Knowing if you or a family member has Lynch syndrome can help them to take steps to reduce their risk of developing cancer.

If you have children, they also have a 1 in 2 chance of developing Lynch syndrome. You will need to talk to them as well. Deciding how and when to have this conversation can be difficult. Talk to your children using language they understand and in an age-appropriate way. Children are often more aware of adult worries than we expect. Being open with them can make them feel included and ease their worries.

In general, healthcare providers will not offer genetic testing to people who are under 18, unless there is a concern about childhood cancer.

If you don't have children but you are considering starting a family and have concerns about the risk of Lynch syndrome, it is important to discuss different options with your healthcare provider and genetic counsellor. They will help you make an informed decision.

7. Where can I get more support?

For more information about Lynch syndrome visit:



For more information about Lynch syndrome
visit **[www2.hse.ie](http://www2.hse.ie/conditions)**
/conditions
and search for: 'Lynch syndrome'
or **scan the QR code**



Lynch Syndrome Ireland provide support to
people with the condition. For information,
visit **lynchsyndromeireland.com**
or **scan the QR code**



For more information about Lynch syndrome,
visit **cancer.ie**
and search for: 'Lynch syndrome'
or **scan the QR code**



For more information about Lynch syndrome,
visit **canchoose.org.uk**
or **scan the QR code**

Further information



For more information on the prospective Lynch syndrome database

visit plsd.eu

or **scan the QR code**



For cancer support centres near you

visit www2.hse.ie/conditions

and search for: 'support centres'

or **scan the QR code**

Cancer - bowel



For more information on knowing the signs of bowel cancer and finding it early

scan the QR code

Cancer - early detection



For more information on finding cancer early

scan the QR code

Further information

Cancer - prevention



For more information on cancer prevention

visit **hse.ie**
/cancerprevention

or **scan the QR code**

Cancer - risk reduction



For more information on reducing your risk of cancer

scan the QR code

Cancer - trial



For more information on cancer trials in Ireland

visit **cancertrials.ie**

or **scan the QR code**

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