



# Lynch syndrome

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Information for patients and families





# Lynch syndrome

## Information for patients and families

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## About this booklet

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This booklet will help you understand what Lynch syndrome is. It explains what Lynch syndrome is, how it is inherited and the cancers it can cause. It also tells you about important tests and actions you can take to reduce your risk of cancer or catch and treat early signs and symptoms. Finally, we tell you about how to talk to your family and children about Lynch syndrome and the supports available.

## What is Lynch syndrome?

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Lynch syndrome is an inherited condition. Inherited means that genetic information (DNA) is passed on from a parent to a child. People with Lynch syndrome have an increased risk of developing some types of cancer. Not everyone with Lynch syndrome will develop cancer, but there is an increased risk.

Lynch syndrome affects people of all races and ethnicities all over the world (about 1 in 280 people have it worldwide). Many people don't know they have it.

## What causes Lynch syndrome?

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Before we describe what causes Lynch syndrome we will explain what genes are. Our bodies are made up of many different types of cells. Genes are in most cells of the body. Genes control the way cells grow, repair and die. When something goes wrong in one or more genes a cell can keep growing out of the body's control and lead to cancer. Lynch syndrome is caused by a change (called a 'pathogenic variant') in a gene. Lynch syndrome is caused by changes in one of the following genes:

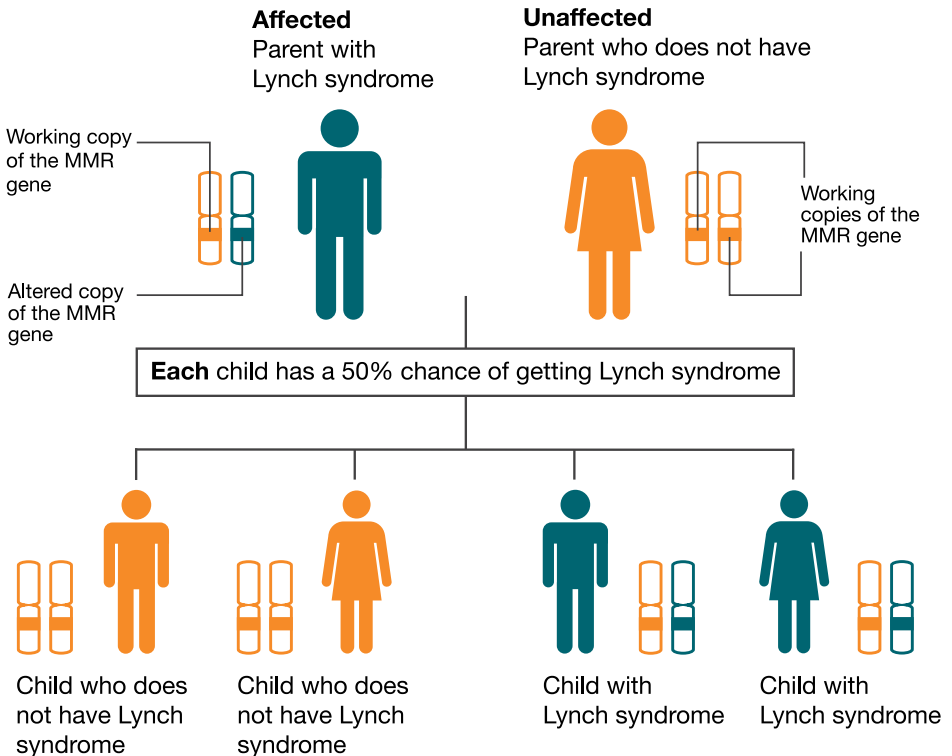
- MLH1
- MSH2
- MSH6
- PMS2
- EPCAM

MLH1, MSH2, MSH6 and PMS2 are called 'mismatch repair (MMR) genes' – genes responsible for fixing errors in your DNA. EPCAM is not a mismatch repair gene, but it can stop MSH2 working as it should.

If you have Lynch syndrome, your risk of developing cancer depends on the gene affected.

## How is Lynch syndrome inherited?

You inherit genes in pairs. You inherit one gene from your biological father and one from your biological mother. If someone has Lynch syndrome, one copy of a MMR gene is altered and does not work properly. If one parent has Lynch syndrome, there is a 1 in 2 (or a 50%) chance of passing on the altered gene (Lynch syndrome) each time they have a child. This is called Autosomal Dominant Pattern of Inheritance.



### Autosomal dominant pattern of inheritance

## What cancers can Lynch syndrome cause?

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People with Lynch syndrome have a higher risk of three types of cancer.

These are:

- bowel cancer (also called colorectal cancer or large bowel cancer)
- endometrial cancer (a form of womb or uterine cancer)
- ovarian cancer.

There is a small increase in the risk of other cancers such as:

- small bowel
- stomach
- pancreas
- gall bladder
- biliary duct
- prostate
- skin
- brain
- kidney
- urinary tract
- bladder

The increased risk of getting these cancers can vary. It depends on:

- the gene that is affected
- your family history of cancer
- your age
- being a man or a woman

## Why do I need to know the signs and symptoms of cancer?

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Knowing the signs and symptoms of cancer can help to find cancer early. Cancer is easier to treat when we find it early, before it has grown bigger or spread to other parts of the body.

**Call your doctor without delay if you develop any symptoms that are not normal for you and are not getting better.**

## What are the symptoms of bowel cancer?

If you have Lynch syndrome, you have an increased risk of some cancers, particularly bowel cancer.

### Symptoms of bowel cancer include:



A change in your bowel habit for more than 6 weeks, such as looser poo, pooing more often or constipation



Feeling like you need to pass a bowel motion even when you know your bowel is empty



Unexplained bleeding from your back passage



Unexplained pain in your tummy or back passage



Unexplained lump or swelling in your tummy



Unexplained weight loss



Feeling very tired all the time, more than is normal for you



Breathlessness more than is normal for you

# What are the symptoms of cancer?

## Symptoms of cancer generally include:



A new lump/bump on your body



A changing lump/bump on your body



Unexplained bleeding



Changes on your skin, for example a new mole or changing mole



Unexplained weight loss



Feeling very tired all the time, more than is normal for you



A new cough lasting for more than 3 weeks



A change in your bowel habit for more than 6 weeks, such as looser poo, pooing more often or constipation



Persistent heartburn or indigestion

**Call your doctor without delay if you have one or more of these symptoms, or any other symptoms that are not normal for you and are not getting better.**

## More information



For tips on spotting cancer early,

visit **hse.ie**  
and search for: 'how to spot cancer early'

or **scan the QR Code**

## What screening and other treatments and interventions might I need if I have Lynch syndrome?

If you have Lynch syndrome, you will need ongoing tests. Let's read below about the management of:

- bowel cancer
- endometrial cancer (a form of womb or uterine cancer)
- ovarian cancer.

There are also tests to check for other types of cancer.

## Bowel cancer

**Regular colonoscopies** – in general, doctors recommend that people with Lynch syndrome have regular colonoscopies to check for bowel cancer.

A colonoscopy is a test to look at your bowel using a small flexible camera. You may start getting colonoscopies as early as 25 or 35 years old. They are repeated every two years. Your healthcare providers will help you decide at what age you should be getting colonoscopies. The age at which you may start getting colonoscopies will depend on the gene that is altered and your medical history.

Getting colonoscopies can help to reduce your risk of cancer. Colonoscopies can help identify and remove any small growths (called 'polyps') from the bowel that might develop into cancer in the future. Regular colonoscopies can also help to find bowel cancer early, before it has caused any symptoms.

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

**Aspirin** – there is evidence that aspirin reduces the risk of bowel cancer in patients with Lynch syndrome. But it may not be suitable for everyone. Speak to your doctor to see if it is an option for you.

## Endometrial cancer and ovarian cancer

Endometrial cancer is a form of uterine cancer. It affects the lining of the womb (endometrium). Knowing the symptoms of endometrial cancer can help to find cancer at an early stage.

The most common symptom of endometrial cancer is abnormal bleeding from the vagina, especially in women who have stopped having periods (post-menopausal women).

You should contact your doctor without delay if you have one or more of these symptoms:

- Abnormal vaginal bleeding or discharge. Abnormal vaginal bleeding is:
  - Increased volume of menstruation (heavier period)
  - Bleeding between periods, after intercourse or after menopause
- Pelvic pain or pressure

## Surgery for endometrial cancer

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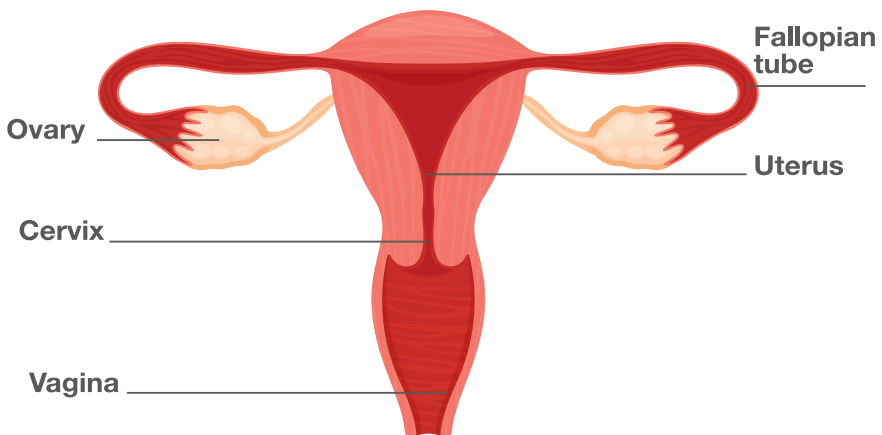
Currently there is no effective screening for endometrial cancer in women. This is because no screening programme has been shown to save lives. If you are a woman aged 35 and over and you have completed your family, you may be offered surgery to remove your uterus and both your ovaries and fallopian tubes. Removing these organs means that cancer

cannot develop in them. It is important to discuss your options with your healthcare team.

For example:

- People with changes in the MLH1, MSH2 and MSH6 genes may be recommended risk-reducing total hysterectomy (TH). This removes their uterus (womb) and removes both their ovaries and fallopian tubes (bilateral salpingo-oophorectomy (BSO)), when their family is complete, no earlier than 35-40 years. The timing should be individualised and take into account endometrial and ovarian cancer risks, family history of cancer, menopause status and comorbidities (health conditions that exist at the same time in one person).
- People with changes in the PMS2 gene may be recommended to undergo total hysterectomy between 40-45 years. The timing should be individualised and take into account endometrial and ovarian cancer risks, family history of cancer, menopause status and comorbidities.

Ovarian cancer is cancer that can develop in the ovary, fallopian tubes and the peritoneum. The ovaries are two small organs that store eggs needed for reproduction. Anyone with ovaries can develop ovarian cancer. The peritoneum is a thin layer that covers the abdominal cavity and covers many of the organs inside the cavity.



**Female reproductive system**

If you are a woman with Lynch syndrome, it is important to talk to your doctor if you develop any of the following symptoms:

**B** is for bloating that doesn't come and go.

**E** is for eating difficulty and feeling full more quickly.

**A** is for abdominal and pelvic pain you feel most days.

**T** is for toilet changes in urination or bowel habits.

### **BEAT symptoms**

## **Surgery for ovarian cancer**

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Currently there is no effective screening for ovarian cancer in women. This is because no screening programme has been shown to save lives. If you are a woman aged 35 and over and you have completed your family, you may be offered surgery to remove your uterus and both your fallopian tubes and ovaries. Removing these organs means that cancer cannot develop in them. It is important to discuss your options with your healthcare team.

For example:

- People with changes in the MLH1, MSH2 and MSH6 genes may be recommended risk-reducing total hysterectomy (TH). This removes their uterus (womb) and removes both their fallopian tubes and ovaries (bilateral salpingo-oophorectomy (BSO)), when their family is complete, no earlier than 35-40 years. The timing should be individualised and take into account endometrial and ovarian cancer risks, family history of cancer, menopause status and comorbidities.
- People with changes in PMS2 genes maybe recommended to have a bilateral salpingo-oophorectomy (BSO) in addition to their total hysterectomy (TH) depending on family history or other factors.

## Other types of cancer and tests

If you have Lynch syndrome, you may be offered tests for other types of cancer. We look at two here: stomach cancer and skin cancer.

### Stomach cancer

**Helicobacter pylori testing** – you may also be offered one-off testing for *Helicobacter pylori*. *Helicobacter pylori* is a bacteria that can be found in your stomach. It can cause an increased risk of stomach ulcers and stomach cancer. Your doctor can arrange a test. They can do this test by taking a sample of stool (poo) or a breath test.

If you have *Helicobacter pylori*, it can be treated with antibiotics. This can help reduce your risk of stomach ulcers and cancer.

**Regular gastroscopies** – if you have a family history of some cancers, such as stomach cancer, your doctor might recommend regular gastroscopies. A gastroscopy is a procedure where a small flexible camera is used to examine your stomach for changes.

### Skin cancer

You have an increased risk of developing skin tumours if you have Muir Torr  syndrome (MTS). This is a subtype of Lynch syndrome. MTS is caused by an alteration (change) in one of your mismatch repair genes.

**Check your skin** – know what your skin normally looks like and check your skin regularly for changes. If you have any concerns about changes on your skin, contact your GP without delay.

Diagnosing cancer early means it's easier to treat and you have a better chance of a full recovery.

### Other cancer types

**Your healthcare team may recommend other regular tests based on your family history, or as research develops.**

## What can I do to reduce my risk of cancer?

You can make general changes to your lifestyle that will reduce your risk of getting cancer.

Here are some other things you can do to reduce your risk of cancer:

	Eat a balanced diet with high fibre, low fat, and plenty of fruit, vegetables, wholegrains and pulses. Limit red meat and avoid processed meat such as chorizo, bacon or salami.
	Maintain a healthy body weight
	Be physically active, every move counts
	Do not start smoking or if you do try to quit with support from the HSE Stop Smoking service <b><a href="http://www.quit.ie">www.quit.ie</a></b> or call 1800 201 203.
	Avoid alcohol. The less you drink, the lower your risk of cancer.
	Be SunSmart. To reduce your risk of skin cancer, protect your skin and eyes from the sun and never use a sunbed.

## How do I talk to my family about Lynch syndrome?

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If you have a test for Lynch syndrome, your healthcare team will not share the results with your relatives. They will encourage you to discuss your diagnosis with your family. They will also advise you on how to do this. It is important to have as much information as possible to share with them.

Encourage your family members to talk to each other about their health. This can help to identify cancer caused by inherited genes.

## Why is it important to know if you or your family members have Lynch syndrome?

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Knowing if you or a family member has Lynch syndrome can save lives. It can help you to understand your risk of developing cancer so that you can take steps to reduce your risk. Regular testing, for example regular colonoscopies, can help to reduce your risk of cancer or find and treat cancer early.

If your family members do not want to talk about Lynch syndrome, respect their wishes. Let them know you are available if they have questions. You can help them when they are ready to find out more.

### More information



Lynch Syndrome Ireland provide support to people with Lynch syndrome. To learn more, visit [lynchsyrndromeireland.com](https://lynchsyrndromeireland.com) or **scan the QR code**

## How do I talk to my children about Lynch syndrome?

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Lynch syndrome can be a difficult topic to talk to children about. But it is also very important. Talk to your children using language they understand and, in an age-appropriate way. Children are often more aware of adult worries than we realise. Being open with them can make them feel included and ease their worries.

This might include talking about the things you are doing to reduce your risk of cancer. For example, by normalising your colonoscopy experience, you can make it less scary for them to take part in these kinds of tests in the future if they need to.

Remind your children that not everyone with Lynch syndrome gets cancer. But having the information means that people can take steps to reduce their risk.

As your children get older, you may wish to talk to them about whether they want to be tested. You can talk to your genetic counsellor for further advice about how to manage these conversations.

In general, healthcare providers will not offer genetic testing to children and young people who are under 18. However, they may offer genetic testing to them if there is a concern about the risk of childhood cancers. There is a risk of childhood cancers where there is 'constitutional mismatch repair deficiency (CMMRD) syndrome'.

## **What is constitutional mismatch repair deficiency (CMMRD) syndrome?**

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If both parents have Lynch syndrome caused by an alteration in the same gene, some of their children (risk is 1 in 4) will not have any working copies of that gene. They will have 'constitutional mismatch repair deficiency (CMMRD) syndrome'. Children with this condition have an increased risk of childhood cancers such as brain tumours and leukaemia. They may also have bowel polyps (growths in the bowel) and certain skin features such as large flat brown spots on the skin.

If a person is under 18 and they have CMMRD syndrome, their health care professionals may offer genetic testing.

## **What can I do if I have Lynch syndrome, but I don't have children yet?**

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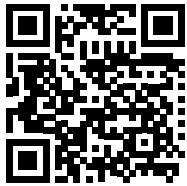
If you are considering starting a family and have concerns about the risk of Lynch syndrome, it is important to discuss different options with your healthcare provider and genetic counsellor. They will help you make an informed decision.

## Further information

### Lynch syndrome



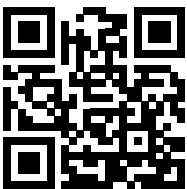
For more information about Lynch syndrome visit [www2.hse.ie/conditions](http://www2.hse.ie/conditions) and search for: 'Lynch syndrome' or **scan the QR code**



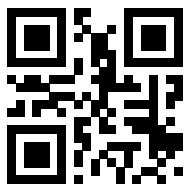
Lynch Syndrome Ireland provide support to people with the condition. For information, visit [lynchsindromeireland.com](http://lynchsindromeireland.com) or **scan the QR code**



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



For more information about Lynch syndrome, visit [canchoose.org.uk](http://canchoose.org.uk) or **scan the QR code**



For more information on the prospective Lynch syndrome database visit [plsd.eu](http://plsd.eu) or **scan the QR code**

## Further information

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### Lynch syndrome - continued



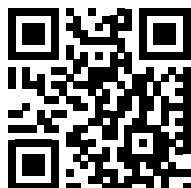
For cancer support centres near you  
visit **[www2.hse.ie](http://www2.hse.ie/conditions)**  
**/conditions**  
and search for: 'support centres'  
or **scan the QR code**

### Cancer - bowel



For more information on bowel cancer,  
visit **[www2.hse.ie](http://www2.hse.ie)**  
and search for: 'bowel cancer'  
or **scan the QR code**

### Cancer - gynaecological



For more information on gynaecological  
cancers in Lynch syndrome,  
visit **[thisisgo.ie](http://thisisgo.ie)**  
or **scan the QR code**

## Further information

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### Cancer - endometrial



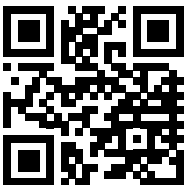
For more information on endometrial cancer,  
visit **[www2.hse.ie](http://www2.hse.ie)**  
and search for: 'womb cancer'  
or **scan the QR code**

### Cancer - ovarian



For more information on ovarian cancer,  
visit **[www2.hse.ie](http://www2.hse.ie)**  
and search for: 'ovarian cancer'  
or **scan the QR code**

### Cancer - trials



For more information on cancer trials in  
Ireland,  
visit **[cancertrials.ie](http://cancertrials.ie)**  
or **scan the QR code**

## **Acknowledgements**

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