



# Information about Lynch Syndrome





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## About this leaflet



This leaflet is about **Lynch Syndrome**.

This leaflet tells you more about:

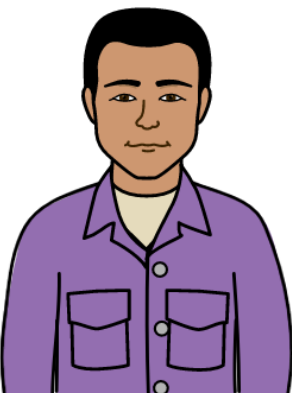
- What Lynch Syndrome is
- What choices you have
- What support you can get.

## What Lynch Syndrome is and how people get it



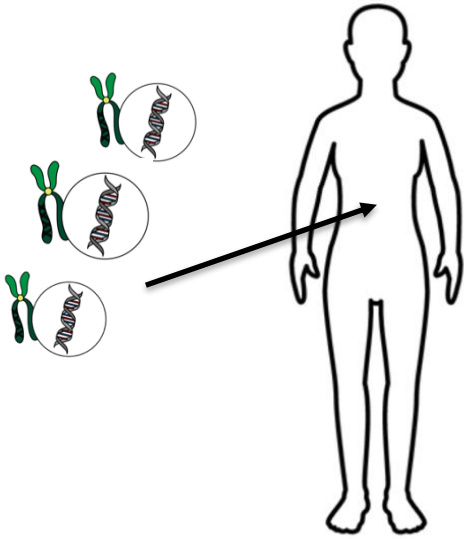
Lynch Syndrome is a health condition.

People with Lynch Syndrome are more likely to get some types of cancer.



But that does not always happen.

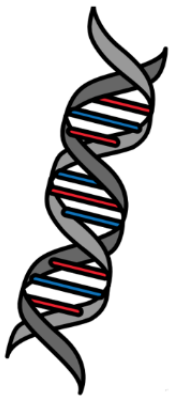
Many people with Lynch Syndrome have a normal life.



Lynch Syndrome happens when there is a change to some things in our bodies called **genes**.

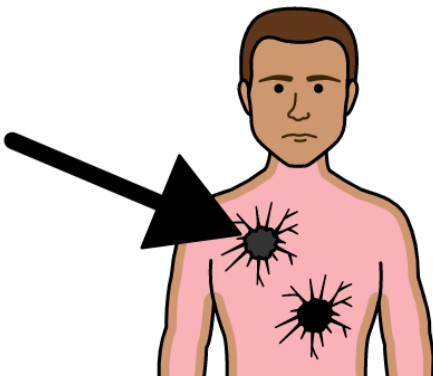
We all have lots of **genes** in our bodies.

They help our bodies to grow and work normally.

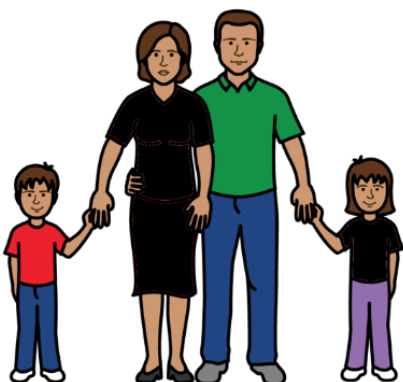


But sometimes the genes can change.

If certain genes change it can cause Lynch Syndrome.



Lynch Syndrome can make it harder for our bodies to stop some cancers from starting.



People with Lynch Syndrome are usually born with these different genes.

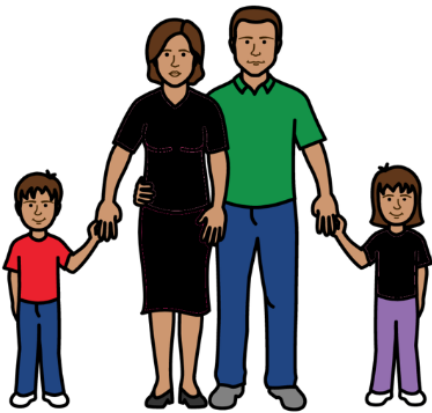
That means they usually get them from their parents.

## How to find out if you have Lynch Syndrome



Doctors can do a test to see if you have Lynch Syndrome.

It is usually a blood test.



You can sometimes get a test if you or people in your close family have had:

- bowel cancer
- womb cancer
- or ovarian cancer.

Close family means your parents, your brother or sister or your children.



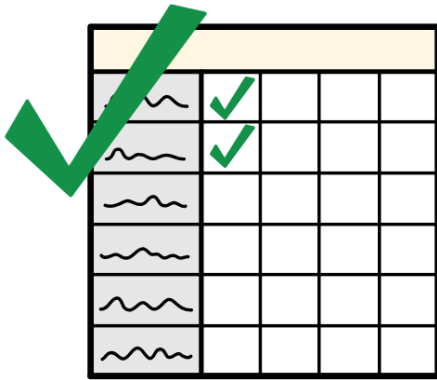
You can ask your doctor about the test if you are worried that you might have Lynch Syndrome.

They will tell you if you can get a test.



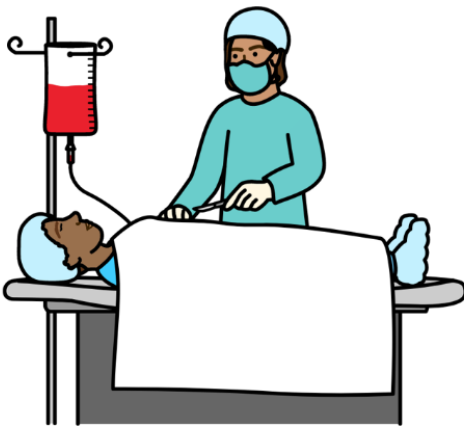
It is up to you if you want the test. You can also say no if you want to.

## What happens next if you have Lynch Syndrome



There are some things to help if you have Lynch Syndrome.

They might give you more chance of stopping cancer or finding it quickly.



For example:

Some people can have an operation to help stop womb and ovarian cancer.

You might have lots of checks with a doctor to see if you might have cancer.

That might include:

- Checking your **bowel** every 2 years
- Checking your **womb** every year if you have one
- Blood tests to see if you might have **prostate cancer**.



Your doctor might also talk to you about:

- Medicines you can take
- Some ways for you to keep healthy.

## The main signs of some cancers

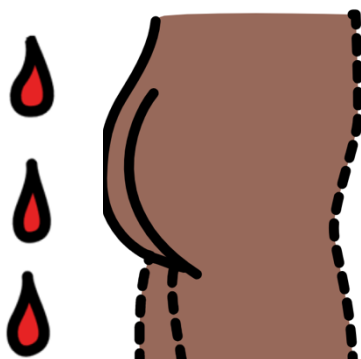


This can help you to know if something might be wrong in your body.

But always check with your doctor if you are not sure.

## Bowel cancer

Some main signs of bowel cancer are:

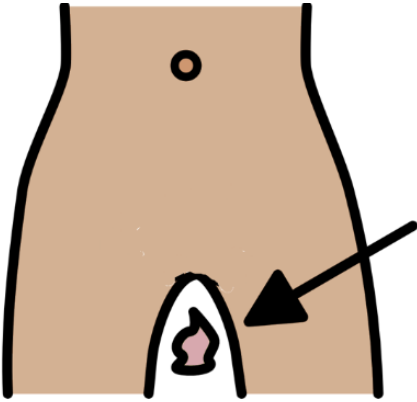


- Bleeding from your bottom or blood in your poo.
- Changes in the way that you do your poo.
- Pain or a lump in your tummy.
- Not feeling hungry much.
- Losing weight for no reason.
- Feeling very tired.

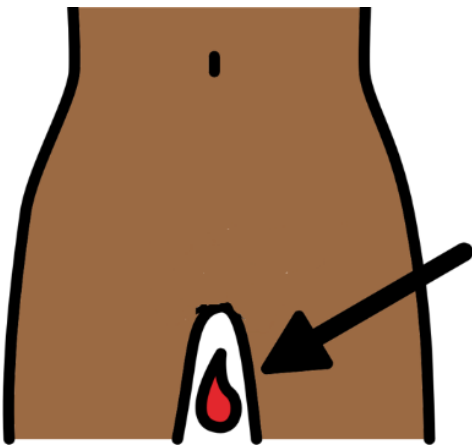
## Womb cancer

Some main signs of womb cancer are:

- Changes to the stuff that comes out of your vagina. This is called discharge.



- Bleeding from your vagina that is not to do with your period.

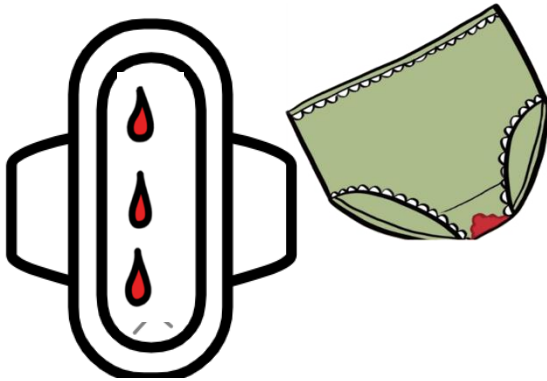


For example, bleeding after the menopause. That is when your periods have stopped for over a year.

Or bleeding after sex.

Or bleeding between your periods.

- Changes to your periods. Like heavy periods or more painful periods.



- Changes to the way you do your poo or wee.



- Pain in your lower back.

# Ovarian cancer

Some main signs of ovarian cancer are:



- Your tummy feeling more round or full than usual.

- Pain in your tummy a lot.

- Feeling unwell after eating.

- Not feeling hungry much.  
Or feeling full quickly after you eat.



- Needing to wee more or wee quickly.

- Changes in the way you do your poo.

- Back pain.

- Feeling very tired.

- Losing weight for no reason.



## Stomach cancer



Some main signs of stomach cancer are:

- Feeling burning in your chest.
- Problems when you swallow food or drink.



- Feeling sick or being sick.
- Black poo.
- Feeling unwell after eating.



- Feeling full quickly after eating.
- Not feeling hungry much.
- Losing weight for no reason.

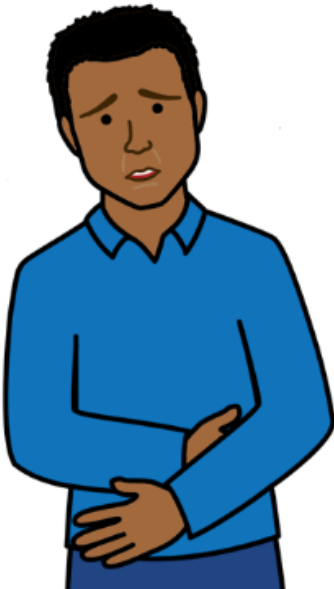
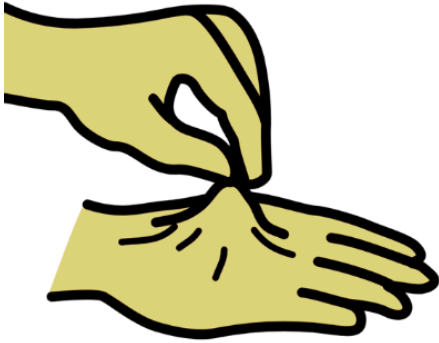


- A lump or pain at the top of your tummy.
- Feeling tired a lot.

## Pancreatic cancer

Some main signs of pancreatic cancer are:

- Yellow skin and eyes.
- Changes to your poo or wee.  
Like a light colour poo or dark wee.
- Changes to the way you do your poo.
- Not wanting to eat much.
- Losing weight for no reason.
- Feeling very tired.
- Feeling sick or being sick.
- Pain in the top of your tummy.
- Pain after eating or your tummy feeling more round or full than usual.



## Prostate cancer



Some main signs of prostate cancer are:

- Needing to wee more or wee quickly.
- Finding it harder to wee.
- Feeling that you still need to wee after you have just been.
- Blood in your wee or semen.

## Urothelial bladder cancer

Some main signs of bladder cancer are:



- Blood in your wee.
- Needing to wee more or wee quickly.
- A burning feeling when you wee.



## Brain cancer

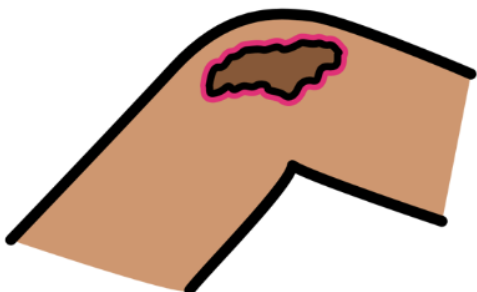
Some main signs of brain cancer are:

- Headaches. They are often worse in the morning or when you cough.
- Having a fit or seizure. This is when your body might shake a lot or you might not know what is happening.
- Feeling sick or being sick.
- Finding it hard to remember things.
- Changes to the way you behave to other people.
- Problems with seeing or speaking.
- Feeling weak.



## Skin tumours

Some people might get a type of cancer on their skin.



# How to get more information or support



It can be hard to find out that you or your family might have Lynch Syndrome.

But there is help for you.

1. You can ask your doctor if you have any questions.



2. You can ask your doctor if you can get support and advice from someone called a **genetic counsellor**.

They should be able to tell you about:

- Lynch Syndrome and how it might affect you or your family.
- The test to find out if you have Lynch Syndrome.
- Your choices and what you can do if you are not sure.

For example, choices about having the test, having medical treatment or having children.



3. You can also get information from our free and private advice service.



It is called **Ask Eve**:

Phone us free on: 0808 802 0019



Or email: [nurse@eveappeal.org.uk](mailto:nurse@eveappeal.org.uk)

With thanks to...

Mencap and all the people with learning disabilities who helped in the making of this guide.

*The development of this resource has been supported by a Grant from GSK, GSK have had no editorial input into the content.*



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