



# Bowel (colorectal) cancer in Lynch syndrome

Information for patients and families





# **Bowel (colorectal) cancers in Lynch syndrome**

Information for patients and families

## **Contents**

---

About this booklet	4
What is bowel cancer?	4
What are my risks of developing bowel cancer if I have Lynch syndrome?	5
What are the symptoms of bowel cancer?	6
How is bowel cancer diagnosed?	8
What are the treatment options for bowel cancer?	9
What can I do to reduce my risk of bowel cancer?	9
Further information	11
Acknowledgements	13

## About this booklet

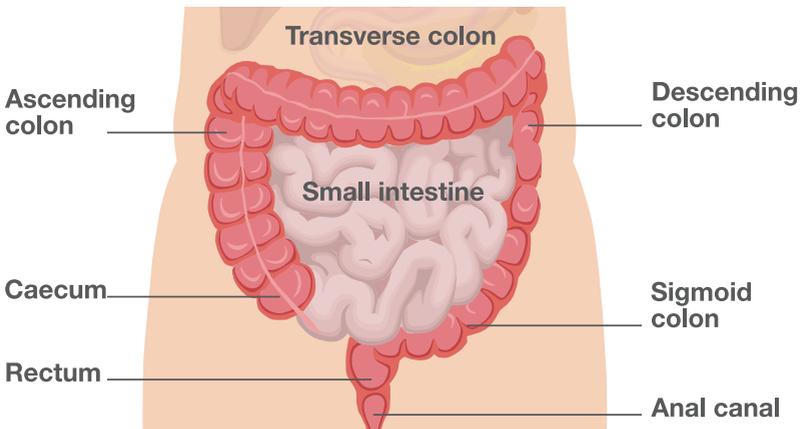
---

This booklet helps you to understand about bowel (colorectal) cancer for people with Lynch syndrome. It explains the signs and symptoms of bowel cancer and how bowel cancer is diagnosed and treated. It also outlines how to reduce your risk of developing bowel cancer.

## What is bowel cancer?

---

Bowel cancer is cancer that starts in the large bowel (colon). Another name for bowel cancer is colorectal cancer.



### Large intestine and colon

Bowel cancer is the most common cancer in people with Lynch syndrome. The average age of a diagnosis of bowel cancer in people with Lynch syndrome is 45. Your risk of getting bowel cancer, and the age at which you may get it, depends on the gene affected.

Most cases of bowel cancer start inside clumps of cells called polyps. Bowel polyps are small growths that can develop on the inner wall of the colon (large bowel) or rectum. A type of polyp called an adenoma may change into cancer over time. This change can happen more quickly in people with Lynch syndrome compared to the general population. However, not all bowel cancers in Lynch syndrome develop from polyps.

# What are my risks of developing bowel cancer if I have Lynch syndrome?

Lynch syndrome is caused by changes in certain genes, which everyone has called mismatch repair (MMR) genes. These genes are responsible for fixing errors in your DNA. These genes are:

- MLH1
- MSH2
- MSH6
- PMS2
- EPCAM

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 bowel cancer in your lifetime ranges from 20-60%. Your risk also depends on which gene is affected.

## More information



To find out about your risk of developing bowel cancer in Lynch syndrome check out the Prospective Lynch syndrome database (PLSD) on [plsd.eu](http://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.

Your risk of getting cancer is affected by lots of things.

This includes:

- things you can't change, like your genes
- things you can change, like your lifestyle habits

Things you can't change include:

- your family history of cancer
- ageing

Things you can change include:

- eating too much red and processed meat such as chorizo, bacon or salami
- eating too little fibre
- living with overweight or obesity
- being physically inactive
- smoking tobacco
- drinking alcohol.

## **What are the symptoms of bowel cancer?**

---

Knowing the symptoms of bowel cancer can help to find cancer at an early stage. You should contact your doctor without delay if you have one or more of the symptoms shown on the next page.

## 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

Your doctor might take blood tests or refer you for a colonoscopy. A colonoscopy is a test to look at your bowel.

## How is bowel cancer diagnosed?

---

### Colonoscopy

Bowel cancer is diagnosed using a colonoscopy. A colonoscopy is a test to look at your bowel using a small flexible camera. The camera is passed through your bottom (anus) and into your bowel. A biopsy (small tissue sample) can be taken when you are having a colonoscopy and sent to a lab for testing to find out whether you have bowel cancer.

A colonoscopy is usually performed at an outpatient appointment, which means you will be in and out of the hospital on the same day. You may be given some medication if you want it to help you to relax during the colonoscopy. This may include sedation and pain medication. If you have sedation you will need someone to collect you after the procedure. Some people opt to have a colonoscopy without sedation.

Your bowel needs to be empty when you have a colonoscopy. The hospital will get you to eat a special diet for a few days beforehand. You will also need to take a strong laxative to help empty your bowel on the day before your procedure or on the morning of the procedure.

Regular screening colonoscopies will be advised from age 25 or 35, depending on the MMR gene variant, to age 75 to 80. You will also be offered a colonoscopy if you have symptoms which could be caused by bowel cancer.

A person with Lynch syndrome may need to have colonoscopies about every two years. Having regular colonoscopies means there is a better chance of picking up cancer early in people with Lynch syndrome. The age to start colonoscopies will depend on which Lynch syndrome gene is affected.

For example:

- people with changes in the MLH1 and MSH2 genes have a higher risk of bowel cancer and may be advised to start getting colonoscopies from the age of 25.
- people with changes in the MSH6 or PMS2 genes may be advised to start getting colonoscopies from the age of 35.

Bowel cancers can grow more quickly in people with Lynch syndrome compared to the general population. So, it is very important to attend for regular colonoscopies.

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

## What are the treatment options for bowel cancer?

---

Some people with bowel cancer will have an operation to remove part of their bowel.

Depending on what part of your bowel is affected, and what type of surgery you have, you may need to have a stoma.

A stoma allows your bowel motion to pass through an opening on your tummy, instead of the back passage. A bag collects the bowel motion. The bag may be put in place using an ileostomy (opening into the small bowel) or a colostomy (opening into the large bowel). You may need a stoma for a temporary period, or you may need one permanently.

### More information



For more information on living with bowel cancer

visit **www2.hse.ie**  
and search for 'bowel cancer'

or **scan the QR code**

You may need chemotherapy, radiotherapy or both to treat your cancer. There are other treatments like immunotherapies, used to treat bowel cancer, if required. Immunotherapies are treatments that boost or change how the immune system works so they can find and attack cancer cells.

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

---

If you have Lynch syndrome, it is important to attend for your regular colonoscopies if your doctor recommends these. Having regular

colonoscopies means that polyps that could develop into cancer can be removed from your bowel to help stop cancer from developing in the future. Colonoscopies can also help find bowel cancer early, before it causes any symptoms.

Taking aspirin can 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.

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 <a href="http://www.quit.ie">www.quit.ie</a> or call 1800 201 203.
	Avoid alcohol. The less you drink, the lower your risk of cancer.

## 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**

## Further information

### 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 about living with bowel  
cancer  
visit **[www2.hse.ie](http://www2.hse.ie)**  
and search for: 'Living with bowel 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**

---

Thank you to the NCCP Lynch syndrome patient advisory group, including Lynch Syndrome Ireland, for its invaluable support and input into the development of this booklet.





**National Cancer Control Programme,  
King's Inns House,  
200 Parnell Street,  
Dublin 1.  
D01 A3Y8**

Tel: **01 8287100**  
Email: **info@cancercontrol.ie**

**www.hse.ie/cancer**  
Twitter: **@hseNCCP**

**NCCP-COM-087**

Bowel (colorectal) cancer in Lynch syndrome.  
Information for patients and families.

Produced by: **HSE NCCP**  
Print date: **December 2025**  
Review date: **December 2028**  
Product code: **HCC01842**

