A guide to
LYNCH SYNDROME

the eve appeal

FOREWORD

Year-on-year, we learn more and more about cancer – why it develops, ways to prevent it, how to spot it, and how best to treat it. The more we know, the more we can do to help save lives.

Some people have an increased risk of cancer

There are many things that either cause or contribute to someone getting cancer. These can be related to lifestyle, environment, or simply as a result of a person's genetic makeup. Being at an increased risk of cancer does not mean you will develop it, but it does make it more likely, so it is important to be aware of symptoms and get any worrying changes checked.

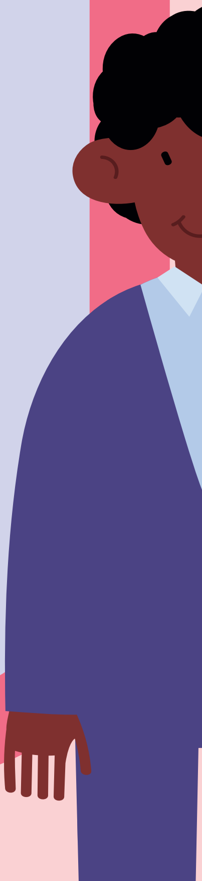
Lynch Syndrome and understanding your options

People with Lynch Syndrome are at a higher risk than the general population of developing some cancers. Identifying people who have Lynch Syndrome can have important benefits, including prevention of cancer, spotting it early and helping doctors decide on the best treatment for people who do develop cancer.

If you have been impacted by a diagnosis of Lynch Syndrome, you are not alone. Around 25 million people across the world live with this syndrome.[i] Most people with Lynch Syndrome live a normal life; however, being diagnosed with it does carry important considerations – for individuals and families.

This booklet aims to help you understand more about the syndrome, what your options are, and the support that is available. When making a decision – make sure you have the right information and never be afraid to ask questions. Ask Eve, The Eve Appeal's nurse-led information service, is here to listen, and we are always happy to help.

Tracie Miles,
Ask Eve Cancer Information Nurse



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Contact

For more information, you can contact The Eve Appeal's nurse-led information line, **Ask Eve.** It is completely free and confidential.

Email: **nurse@eveappeal.org.uk**
Call: **0808 802 0019**
Website: **www.eveappeal.org.uk**

A BIT ABOUT LYNCH SYNDROME

Cells, genes and DNA

Nearly every cell in our body contains DNA. This acts as a set of instructions for how our cells function and grow.

DNA contains thousands of genes, which each contain a small piece of the information our bodies need to function.

What happens when genes get altered?

The genes that we are born with quite commonly have changes in their code called gene alterations, sometimes referred to as gene ‘mutations’, or ‘variants’. Having gene alterations is quite common. However, the impact can vary from nothing at all to being potentially quite serious.

What is Lynch Syndrome?

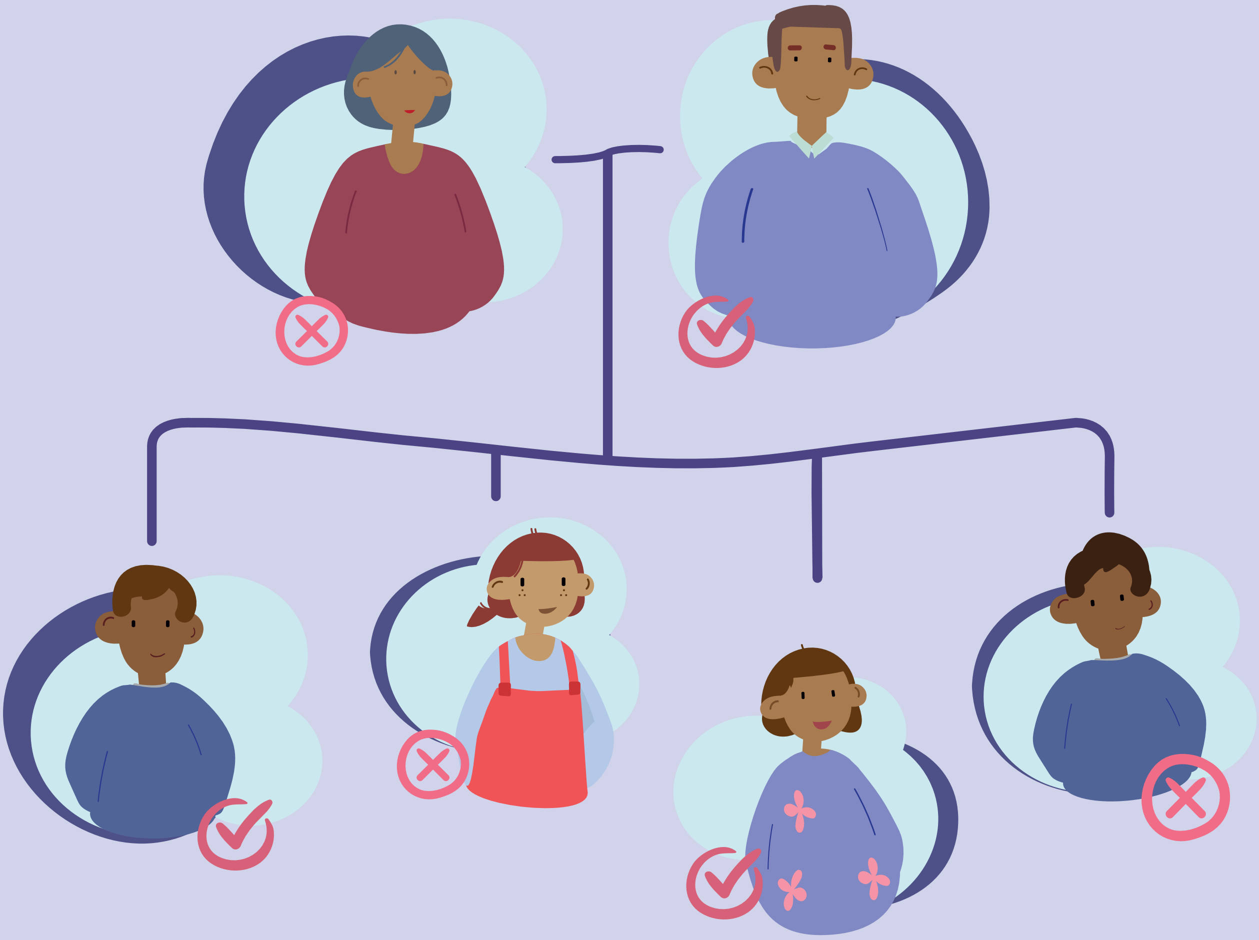
Lynch Syndrome is a condition which increases a person’s risk of certain cancers. It is caused by an alteration in one of five different genes (MLH1, MSH2, EPCAM, MSH6 and PMS2).

> **“Many people with Lynch might never get cancer, but if I do, I know the choices I've made to get my Lynch diagnosis, ensuring I have my regular surveillance, and being aware of the symptoms I should be on the lookout for, will mean I'm in the best possible position should the worst happen. I was 25 when I was diagnosed with Lynch; I’m now in my early 30’s and whilst I still have what I’ve called ‘Lynch wobbles,’ they are fewer and less frequent, and with the knowledge of how underdiagnosed Lynch is, I feel in such a privileged position to have access to screening, information and support.”**

Helen

How do you get Lynch Syndrome?

Lynch Syndrome is usually inherited (or 'hereditary') but can very occasionally occur with no family history – this is known as 'sporadic alteration'. Typically, you will inherit Lynch Syndrome from your mother or your father. If one parent has Lynch Syndrome there is a 1 in 2 (50%) chance that each of their children will have it.



How common is it?

It is thought that around 1 in every 400-450 people have Lynch Syndrome. It is estimated that around 175,000 people in the UK could be living with Lynch Syndrome, although up to 95% may not be aware of it.[ii]

Why does Lynch Syndrome increase the risk of some cancers?

In our cells, there are natural processes that defend us from cancer – from repairing damaged DNA to destroying potentially dangerous cells. In Lynch Syndrome, the ability to properly 'proofread' newly formed DNA is lost. This means that any errors are not spotted or corrected. These errors can build up, eventually affecting the bodily processes that usually prevent cancer formation. When this happens, an individual is at a greater risk of developing cancer.

RISK OF CANCER FOR PEOPLE WITH LYNCH SYNDROME

How likely is it that someone with Lynch Syndrome will develop cancer?

While many people with Lynch Syndrome will not develop cancer, links have been found to a range of different types.

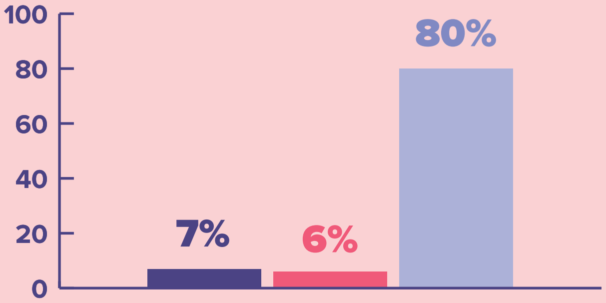
Lynch Syndrome mainly carries a risk of developing bowel and womb cancer, but it also increases the risk of other cancers like ovarian, stomach, pancreas, prostate, urethral, kidney, brain, as well as skin tumours.

Being diagnosed with Lynch Syndrome may take some time to get used to. The information gained from the test is important because it can guide doctors to enrol you on surveillance programmes to help spot cancers early when they are easiest to treat. Further, doctors can sometimes prescribe preventative medicines and treatments, known as personalised medicines. A Lynch Syndrome diagnosis also gives people an opportunity to assess lifestyle changes that can reduce the risk of cancer.

PLEASE NOTE: Depending on the gene alteration, the risk of cancer will be different.

For gene-specific information, please read: The Royal Marsden's **beginner's guide to Lynch Syndrome** or use the Prospective Lynch Syndrome Database (PLSD) **risk calculator**

BOWEL CANCER



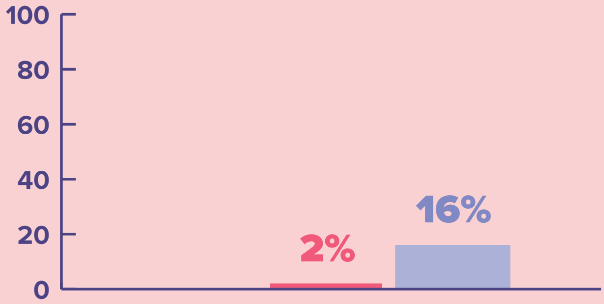
GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 15 for males (7%)[iii]

LIFETIME RISK IN FEMALES*
1 in 18 for females (6%)[iii]

LIFETIME RISK WITH LYNCH SYNDROME**
Up to 4 in 5 people (80%)[ii]

OVARIAN

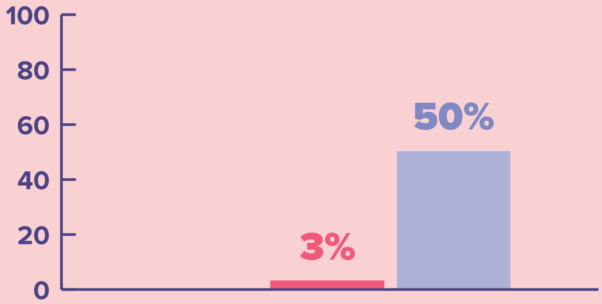


GENERAL POPULATION

LIFETIME RISK IN FEMALES*
1 in 50 for females (2%)[iv]

LIFETIME RISK WITH LYNCH SYNDROME**
Up to 1 in 6 people (16%)[v]

WOMB (endometrial/uterine)

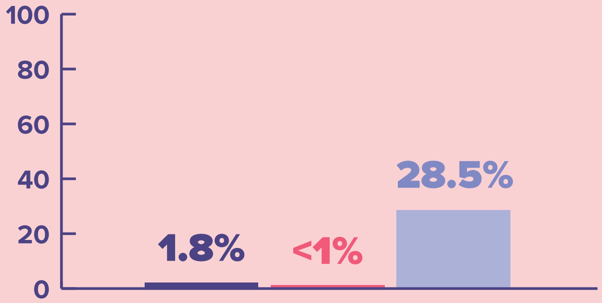


GENERAL POPULATION

LIFETIME RISK IN FEMALES*
1 in 36 for females (3%)[vi]

LIFETIME RISK WITH LYNCH SYNDROME**
Around 1 in 2 females (50%)

UROTHELIAL



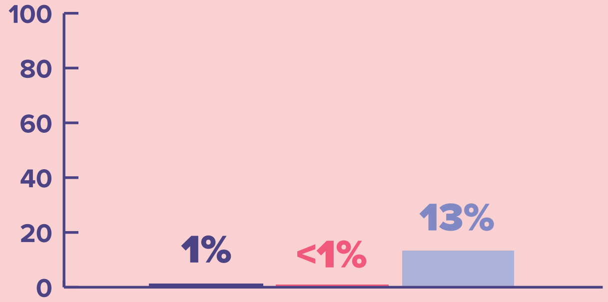
GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 55 for males (1.8%)[1,vii,viii]

LIFETIME RISK IN FEMALES*
1 in 143 for females (<1%)[2, vii, viii]

LIFETIME RISK WITH LYNCH SYNDROME**
Up to 1 in 4 people (28.5%)[ix]

STOMACH (Gastric)



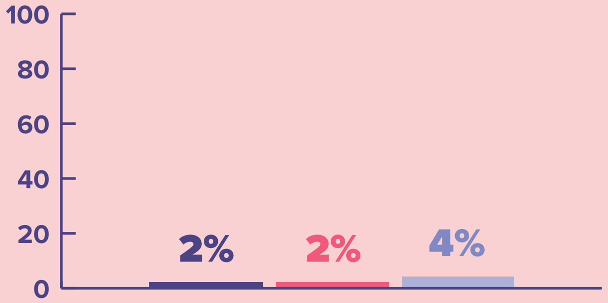
GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 76 for males (1%)[x]

LIFETIME RISK IN FEMALES*
1 in 130 for females (<1%)

LIFETIME RISK WITH LYNCH SYNDROME**
Around 1 in 5 people (13%)[xi]

PANCREAS



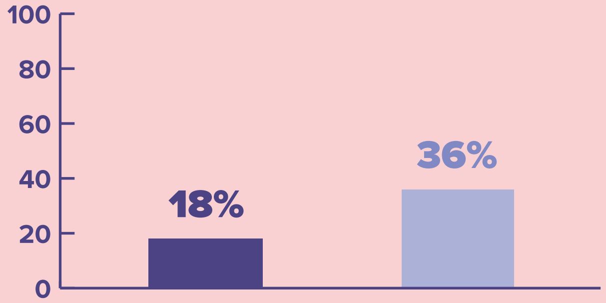
GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 53 for males (2%)[xii]

LIFETIME RISK IN FEMALES*
1 in 57 for females (2%)[xii]

LIFETIME RISK WITH LYNCH SYNDROME**
Up to around 1 in 25 people (4%)[xiii]

PROSTATE

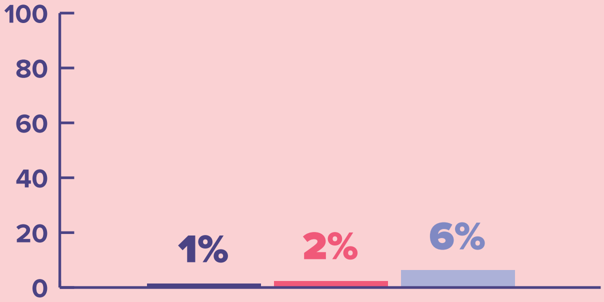


GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 6 for males (18%)[xiv]

LIFETIME RISK WITH LYNCH SYNDROME**
Estimated to be around 1 in 3 people (36%)[xv]

BRAIN



GENERAL POPULATION

LIFETIME RISK IN MALES*
1 in 69 for males (1%)[xvi]

LIFETIME RISK IN FEMALES*
1 in 65 for females (2%)

LIFETIME RISK WITH LYNCH SYNDROME**
1 in 17 for males (6%)
1 in 16 for females (6%)[xvii]

*Estimates of general lifetime risk are typically based on adults in the UK born after 1960, although this may vary in some cases.

**Estimates for lifetime risk in Lynch Syndrome are based on available data; but it can vary depending on lots of factors such as which gene is altered, your age, sex and lifestyle.

***Muir Torre Syndrome (a type of skin tumour) also have an increased lifetime risk for people with Lynch Syndrome, but the data is not currently available to accurately include these in the above diagram.

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[1] Calculated based on 1 in 50 lifetime risk of bladder cancer, multiplied by 90% of bladder cases being caused by urothelial tumours

[2] Calculated based on 1 in 130 lifetime risk of bladder cancer, multiplied by 90% of bladder cases being caused by urothelial tumours

TESTING FOR LYNCH SYNDROME

Lynch Syndrome is identified through a genetic test. The testing may be slightly different depending on whether you have been diagnosed with cancer, or if you are being tested because a relative has been diagnosed with Lynch Syndrome (‘predictive genetic testing’). If you are diagnosed with certain cancers, you may be automatically tested for gene alterations.

I’ve got a history of cancer in my family, should I get tested for Lynch Syndrome?

Cancer is quite common. However, if you have a family history of cancer (particularly bowel and womb cancer) there is the possibility that it could be linked to Lynch Syndrome. The only way to be sure of whether you have Lynch Syndrome in your family is for you or any close family members (siblings, parents, children) to be referred to a genetics specialist who will provide genetic counselling and advice on getting tested. Genetic counselling provides emotional support and information to help you and your family with making health decisions. Speak to your GP if you would like to discuss getting referred.

You may be eligible for genetic testing for Lynch Syndrome if:

- You have two or more close family members (sibling, parent, child) who have had bowel cancer, womb or ovarian cancer
- You or a close relative has had bowel or womb cancer at a young age (under 50)

Can anyone be tested for Lynch Syndrome?

Unless there is a strong likelihood that you may have Lynch Syndrome, you are unlikely to be able to access predictive genetic testing for free on the NHS.

Lynch Syndrome does not skip generations. If you do not have a gene alteration associated with Lynch Syndrome – even if your parent or sibling does – you will not pass it on to any children or grandchildren.

What does a Lynch Syndrome genetic test actually look for?

When looking to see whether a person has Lynch Syndrome, the test looks for alterations in five different genes. These are called:

MLH1 **MSH2** **MSH6**

PMS2 **EPCAM**

The cancer risks are slightly different for each gene, so it is important for both the clinical team and the individual to know which specific alteration is present. Keep in mind that, even if alterations are found during testing, their impact can vary from being potentially serious to nothing at all and many people with Lynch Syndrome live a normal life.

What does the test for Lynch Syndrome involve?

Lynch Syndrome is diagnosed by testing for the presence of specific altered genes in a person's DNA. The NHS typically uses a blood test.

If you have a cancer that doctors suspect is linked to Lynch Syndrome…

In this case, doctors will initially conduct some tests on the tumour that has been removed. If these tumour tests suggest you could have Lynch Syndrome, your doctor will discuss this result with you. You will be invited to have a blood test to diagnose Lynch Syndrome. As this test is complex, results may take weeks or months. Your clinical team will be able to advise how long you may have to wait for your results.

If you are a relative of someone who has been diagnosed with Lynch Syndrome…

If you decide after genetic counselling to have a test (known as 'predictive testing'), a blood sample is tested in a lab to see if you have the same gene alteration found in your family member with Lynch Syndrome.

WHY KNOWING MATTERS

Can knowing I have Lynch Syndrome help reduce the chance of getting seriously ill from cancer?

While it is not yet possible to completely remove the risk of cancers related to Lynch Syndrome, being diagnosed offers the opportunity to take steps to minimise the risk. Some of these steps include:

① **For women and people with gynaecological organs, you may be offered risk-reducing surgery which will prevent womb and ovarian cancer from developing.**

② **Attending regular cancer surveillance:**

  a. This may include having a regular colon and rectal examination, which is called a colonoscopy
  b. For women and people with gynaecological organs, surveillance may include getting your womb checked, called a hysteroscopy[xviii]
  c. For men and people with a prostate, surveillance may include a prostate examination
  d. You may be offered *Helicobacter pylori* testing, which is important part of stomach (gastric) surveillance

③ **Lifestyle changes may be advised, such as weight loss, quitting smoking, or reducing alcohol consumption.**

④ **It's really important to become more aware of the signs of cancer and know what to do if these are spotted.**

⑤ **You may discuss the use of daily aspirin with your doctor, as it has been shown to greatly reduce bowel cancer risk in people with Lynch Syndrome.**[xix]

What is cancer surveillance?

Surveillance means regular check-ups to see if there are any early signs of cancer, including any precancerous changes (such as bowel polyps), so that any disease can be found as early as possible, when they are more treatable. If anything is discovered, steps can be taken to address the problem quickly. If you have been diagnosed with Lynch Syndrome, you can discuss surveillance options with your clinical team, genetic counsellor, or your GP.

What if I do not want to find out if I have Lynch Syndrome?

It's completely your choice whether to have genetic testing for Lynch Syndrome and it should only be done after careful consideration. There is help on hand to support you, whatever the outcome. This could include speaking to a specialist genetic counsellor about what to say to family members, or your options for regular cancer surveillance. For further information and support, Ask Eve is always on hand, as well as peer support from Lynch Syndrome UK. You can find more details on how to access support at the end of this booklet on page 25.

Tom

"No-one wants to be told they have Lynch Syndrome, let alone cancer. I found out that I had both within 48 hours. Despite this, I still consider myself pretty lucky. Acting quickly on this information almost certainly saved my mother's life. As soon as they learned that my cancer was caused by Lynch Syndrome, my parents got themselves checked, even though they had no symptoms. Unfortunately, during one of these checks, my mum discovered that she had a tumour at each end of her colon, but it had been caught early. Like me, she is now more than 3 years cancer free and is able to live a normal life."

LIVING WITH LYNCH SYNDROME

Finding out if you or a loved one has a condition that could increase the risk of cancer is not easy and it is understandable to feel anxious regarding your own future and that of your family. Over the past few years, as our understanding of different diseases and how they can be passed on through families has improved, a lot of excellent support on these concerns has become available. Below, you can find answers to some of the common questions people ask.

If your question is not included, please do contact the team at Ask Eve, whose contact details are at the front of this booklet.

What cancer surveillance is available?

There are different types of cancer surveillance available that check the organs at risk of developing cancer. What surveillance is offered will depend on what mutation is present, this will be guided by the genetic

Bowel, Colon

People living with Lynch Syndrome will be invited to attend regular bowel surveillance. You will usually be invited to attend bowel checks from the age of 25 (this is the age at which the risk of bowel cancer for people with Lynch Syndrome increases). You may be invited from a slightly younger age if you have a relative who had bowel cancer before the age of 30.

Bowel checks should take place every two years and involve a colonoscopy, which is when a long flexible tube with a camera on the end is gently inserted through the anus and along the bowel. The camera looks for polyps and abnormalities in the bowel which, can be removed or treated. Most polyps are harmless, but they can develop into cancer if left for a long time. Any signs of cancer can also be spotted early when they are more treatable.

It’s important to have an empty bowel before the procedure, so you will be given a special diet to follow for a couple of days before, along with strong laxatives to help clean the bowel. To keep you comfortable during the procedure you will be given a mild sedative. Most people can leave the hospital on the same day.

Womb (uterus) and ovaries

While there is no firm protocol on the surveillance of the ovaries and womb in people living with Lynch Syndrome, research is currently being undertaken to understand the best approach. This makes knowing what is normal for you and the symptoms to look out for even more important. If you have any worries or concerns about surveillance or symptoms, do contact Ask Eve using the details on the next page.

One surveillance option women and people with gynaecological organs may be offered is a 'transvaginal' ultrasound scan (through the vagina) to measure the thickness of the lining of the womb. Some people may also be offered a hysteroscopy, which is a procedure to look at the inside of the womb.

A hysteroscopy involves a narrow telescope with a small camera at the end being passed into the womb through the vagina and cervix (entrance to the womb). It is carried out on an out-patient or day-case basis, meaning you will not need to stay at hospital overnight. A local anaesthetic (to numb your cervix) may be used. General anaesthetic may be used if you need to have treatment during the procedure, or if it is your preference to be asleep. Hysteroscopies can take a maximum of 30 minutes to carry out but may only take 5 to 10 minutes.

People have varying experiences with hysteroscopies; some feel no pain or only a mild pain or discomfort, while some can find the pain severe. If you find the procedure too uncomfortable, tell your nurse or doctor as they can stop at any time. You can also speak to your doctor or nurse before the hysteroscopy if you are nervous or would like to ask about pain relief.

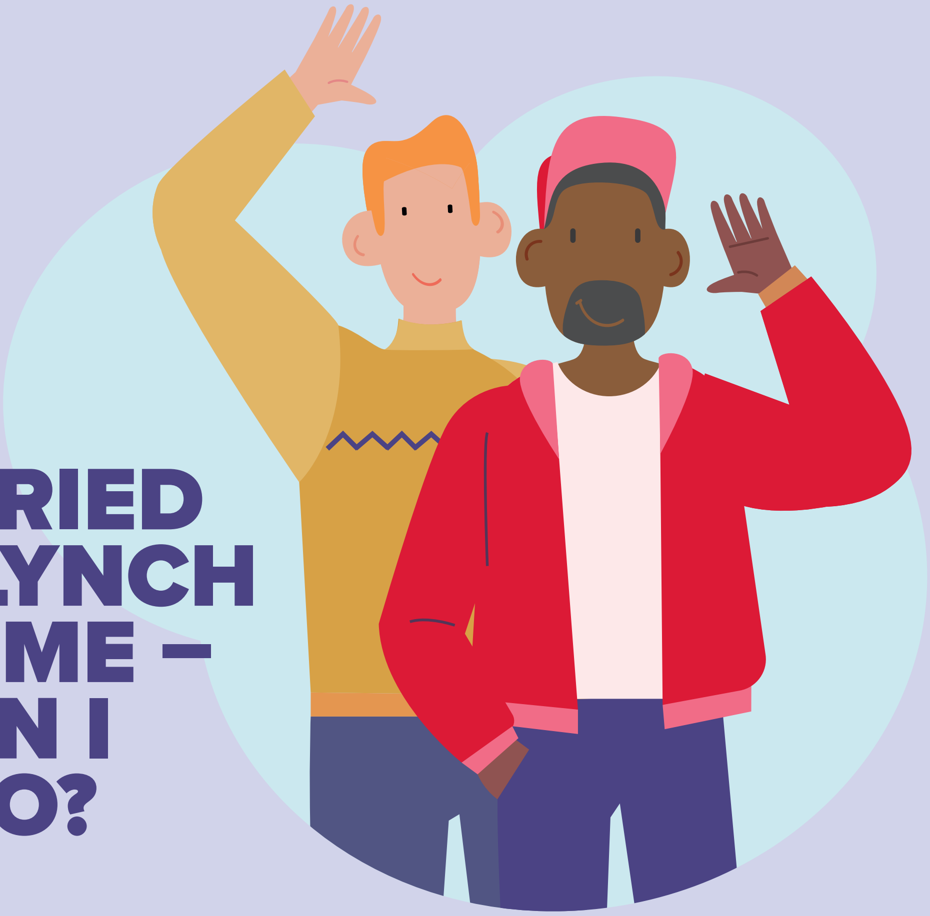
Ovarian cancer surveillance is not widely offered as there is little evidence to show it is effective.

Prostate

Surveillance for prostate cancer in people living with Lynch Syndrome is also less concrete than bowel surveillance.

A blood test to check Prostate-Specific Antigen (PSA) levels, which is a marker in blood that can rise if you have prostate cancer, can be used for surveillance.

There is ongoing research into the risk of prostate cancer for people who have Lynch Syndrome to determine whether targeted annual PSA testing from the age of 40 could lead to earlier diagnosis.



I'M WORRIED ABOUT LYNCH SYNDROME – WHO CAN I SPEAK TO?

Whether you have been diagnosed with Lynch Syndrome, or someone close to you has, there are a range of options where you can find information and support. Ask Eve is a good place to start, as well as patient support group Lynch Syndrome UK (details on page 25). Another option is to speak with a genetic counsellor, which may require a referral from either your GP or your cancer team.

I have Lynch Syndrome – how can I tell my children or grandchildren they may be at risk?

If you are worried about telling family, there are many support resources that can help. These include advice from genetic counsellors who have specialist expertise in this area. There are also discussion guides that can help you introduce the topic and explain the situation to your family so they can make informed decisions about what they should do.

The Royal Marsden has some helpful information about this:
A beginner's guide to Lynch Syndrome

Will genetic testing and finding out I am positive for Lynch Syndrome affect my ability to get insurance, travel, get a mortgage etc? Is it better not to know?

Sometimes people are concerned that undergoing predictive genetic testing could have a negative impact on their ability to take out life insurance. However, there is an agreed code of practice between insurance companies which means that ABI insurers will not use the results of genetic testing for high-risk cancers to calculate premiums or eligibility for life insurance. If you would like more information, you can **visit www.abi.org.uk.**

This information is accurate at the time of printing, but rules may have changed by the time you read this. We would recommend checking the ABI website or speaking to your genetic counsellor.

What if I want to have children in the future?

You may have questions about this if you are planning to start a family now or in the future. There are a number of possible routes you could take, including having children naturally; adopting; egg or sperm donation from someone who does not have Lynch Syndrome; prenatal testing; and pre-implantation genetic diagnosis (PGD) – this is where you undergo IVF to test your embryos for Lynch Syndrome and only those which do not carry the gene alteration are put in your or your partner's womb. A genetics specialist will be able to guide you through these options and help you decide which route might be best for you.

Can I have Hormone-Replacement Therapy (HRT) if I have Lynch Syndrome?

If you have Lynch Syndrome and have not been diagnosed with cancer, HRT can be taken under the advice of your GP or specialist healthcare team. If you have had cancer, the decision to take HRT will need to be discussed with your oncology team.

If you had preventive surgery for Lynch Syndrome whilst premenopausal (removal of your womb, fallopian tubes and ovaries), then oestrogen only HRT will be prescribed until the natural age of menopause. You can discuss your options with your clinical team.

SYMPTOMS TO BE AWARE OF

If you or someone you know has been diagnosed with Lynch Syndrome, it is important to be aware of some of the symptoms of cancer. It's always good to be aware of your own body and what's normal for you so that if something feels wrong, you can get it checked.[xx]

Spotting cancer early often means it is more treatable, with many of the treatment options being less invasive or aggressive. This means there is a better chance of a positive outcome and of living a fuller, healthier life. In the following section, you will find more information on some of the common signs to look out for.

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Not all of the cancers listed will apply to everyone with Lynch Syndrome, as the risk of different cancers depends on the specific gene alteration. If you have any concerns – even if your symptom is not listed here – you should make sure that you discuss these with your GP or specialist. Ask Eve is also on hand to help, and the contact details are at the front of this booklet.

Mo

"I discovered Lynch Syndrome after a stage 4 bowel cancer diagnosis at the age of 31. My cancer continued to grow after the regular chemotherapy failed. I was classed as having terminal cancer after there was no more treatment available. The cancer was spreading. Lynch cancers need to be treated differently. Thankfully the science and research continued to develop, which showed immunotherapy as an option. Incredibly the treatment worked and now at the age of 39 I am cancer free."

SYMPTOMS TO BE AWARE OF

Bowel cancer

Bowel cancer describes cancer that begins in the large bowel. This is made up of the colon and rectum. Depending on where the cancer starts, it can sometimes be called either colon or rectal cancer. Symptoms of bowel cancer include:

- **Bleeding from your bottom and/or blood in your poo – which happens for no obvious reason or is associated with a change in bowel habit or mucus**
- **Ongoing change in your bowel habit – this usually means having to poo more regularly than normal and your poo may also become more runny; you may also notice your poo becomes very dark and smells more offensive**
- **Persistent pain or lump in your tummy (lower abdominal), bloating and discomfort – this will be caused by eating**
- **A loss of appetite**
- **Unexplained weight loss**
- **Extreme tiredness – bowel cancer can lead to a lack of iron in the body (anaemia), which can make you feel very tired**

Womb cancer

Womb cancer affects the womb (uterus) and often begins in the lining (endometrium). It is sometimes called uterine or endometrial cancer. The main symptoms of womb cancer are:

- **Bleeding, spotting or abnormal discharge from the vagina after the menopause (if you haven't had a period for a year or more, any bleeding is considered abnormal and should be checked by a GP)**
- **Heavier or more painful periods than are usual for you**
- **Bleeding between periods**
- **Bleeding after sex**
- **Blood-stained vaginal discharge (pink, red, brown)**
- **Change in your bowel or urinary habits**

Other symptoms of womb cancer include lower back or pelvic pain.

Ovarian cancer

Ovarian cancer occurs in one or both of the two small organs (ovaries) that store the eggs needed for reproduction. Anyone with ovaries can develop ovarian cancer.

The main symptoms of ovarian cancer include experiencing the following frequently (approximately 12 or more times per month):

- **A persistent swollen tummy or feeling bloated (that doesn't come and go)**
- **Pain or tenderness in your tummy or slightly lower between your hips**
- **Lack of appetite or feeling full quickly after eating**
- **The urgent need to wee, or needing to wee more often**

Other symptoms include:

- **Indigestion**
- **Constipation or diarrhoea**
- **Back pain**
- **Fatigue**
- **Unexplained weight loss**

Stomach cancer (gastric)

Stomach cancer is a cancer that begins anywhere in the stomach. Symptoms can be tricky to spot, but include digestive issues such as:

- **Heartburn or acid reflux**
- **Problems swallowing (dysphagia)**
- **Feeling or being sick**
- **Black tarry stool**
- **Indigestion**
- **Feeling full very quickly when eating**

Other symptoms can include:

- **Loss of appetite**
- **Unexplained weight loss**
- **A lump or pain at the top of your tummy**
- **Fatigue**

SYMPTOMS TO BE AWARE OF

Pancreatic cancer

Pancreatic cancer is a cancer that begins anywhere in the pancreas. The pancreas sits just below the stomach in your upper abdomen. It helps digest food and makes hormones like insulin.

It can be hard to spot symptoms of pancreatic cancer and sometimes there aren't any symptoms at all, until the cancer is advanced. However, they can include:

- **Jaundice – when the whites of your eyes and your skin turn yellow; jaundice can also cause you to have itchy skin and make your wee darker and poo paler than usual**
- **Loss of appetite**
- **Unexplained weight loss**
- **Fatigue**

Symptoms can also affect your digestion. For example:

- **Feeling or being sick**
- **Diarrhoea or constipation**

Prostate cancer

Prostate cancer begins in the prostate, a small gland located in the pelvis, in between the penis and bladder.

Prostate cancer can develop slowly, meaning there can be no signs of it for many years. Symptoms typically appear once the prostate has grown large enough to put pressure on the tube that carries urine from the bladder out of the penis (urethra). At this point, symptoms include:

- **An increased need to wee**
- **Needing to wee more at night**
- **Blood in your wee or semen**
- **Sudden urges to wee**
- **Straining while weeing**
- **A feeling that the bladder has not fully emptied**

Urothelial bladder cancer

Urothelial cancer develops from the cells of the bladder lining (urothelium).

Blood in your wee is the most common sign of urothelial bladder cancer. Other less common symptoms include:

- **A need to wee more frequently**
- **Sudden urges to wee**
- **A burning sensation when weeing**

Skin tumours

Skin tumours can occur in people with a certain type of Lynch Syndrome, although it is quite rare. When they occur because of Lynch Syndrome, the condition is typically referred to as Muir Torre Syndrome. More information on this can be found **here.**

Brain cancer

The symptoms of brain cancer depend on which part of the brain the tumour is growing in, but can include:[xxi]

- **Headaches (which are often worse in the mornings, when coughing or straining)**
- **Fits or seizures**
- **Frequently feeling sick or being sick**
- **Problems with memory**
- **Personality changes**
- **Weakness, vision problems or speech problems (which get worse over time)**

NOTES

USEFUL RESOURCES

There are lots of other resources available to help you navigate Lynch Syndrome. We have included a selection of helpful links here:

The Eve Appeal – Lynch Syndrome

Lynch Syndrome UK

Bowel Cancer UK – Lynch Syndrome

Target Ovarian Cancer – Gene Mutations

Macmillan Cancer Support – Lynch Syndrome

Ovacome – Lynch Syndrome

Ovarian Cancer Action – Lynch Syndrome

Cancer Research UK – Inherited genes and cancer types

Birmingham Women's and Children's NHS Trust – Information leaflet for Patients and Families: Lynch Syndrome

The Royal Marsden – A beginner's guide to Lynch Syndrome

East of England Cancer Alliance – Genetic testing for Lynch Syndrome

Prospective Lynch Syndrome Database (PLSD) – Risk calculator

References

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For more information, you can contact The Eve Appeal's nurse-led information line, **Ask Eve.** It is completely free and confidential.

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