



Gynaecological cancers in Lynch syndrome

Information for patients and families



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About this booklet

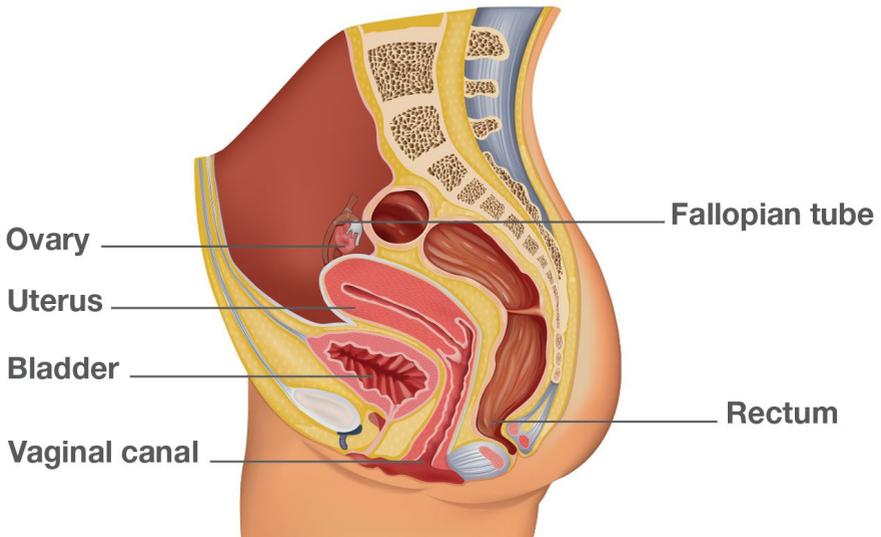
This booklet will help you understand the risk of gynaecological cancer for people with Lynch syndrome. It explains the signs and symptoms of gynaecological cancer and how these cancers are diagnosed and treated. It will also outline how to reduce your risk of developing gynaecological cancer.

What are the gynaecological cancers associated with Lynch syndrome?

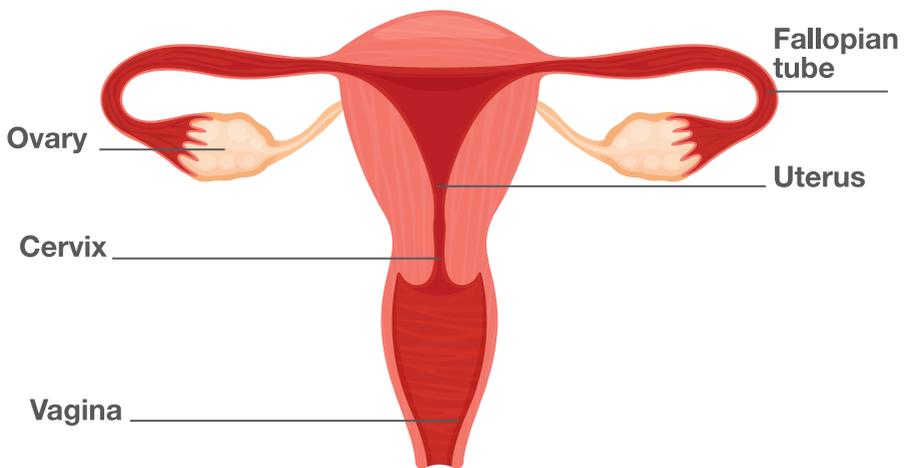
There are two types of gynaecological cancers associated with Lynch syndrome. These are endometrial cancer (a form of uterine cancer) and ovarian cancer.

What is endometrial cancer?

Endometrial cancer is cancer that affects the lining of the womb (endometrium). Another name for womb is uterus. Most cancers of the womb start in the endometrium. Anyone with a womb can develop endometrial cancer.



Female anatomy



Female reproductive system

Endometrial cancer is the most common type of gynaecological cancer in people with Lynch syndrome. Endometrial cancer is often the first cancer that people with Lynch syndrome will have. People with Lynch syndrome are most likely to develop endometrial cancer between 42-61 years of age. Your risk of getting endometrial cancer, and the age at which you may get it, depends on the gene affected.

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

Lynch syndrome is caused by changes in certain genes, including genes we all have 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 endometrial cancer in your lifetime ranges from 10-50% depending on which gene is affected.

More information



To find out about your risk of developing endometrial 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.

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

This includes:

- things you can't change, like your family history, age and your genes
- things you can change, like your lifestyle habits.

Things you can't change:

- ageing
- genetic conditions such as Lynch syndrome
- thickening of the endometrial lining (endometrial hyperplasia)
- having polycystic ovary disease
- taking medicines like Tamoxifen (used to treat breast cancer)
- going through the menopause after the age of 55

Things you can change:

- living with overweight or obesity
- avoiding alcohol
- not being physically active
- taking oestrogen-only HRT

How can I reduce my risk of developing endometrial cancer if I have Lynch syndrome?

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 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.

What are the symptoms of endometrial cancer associated with Lynch syndrome?

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 periods)
- Bleeding between periods, after intercourse or after menopause
- Pelvic pain or pressure

How is endometrial cancer diagnosed?

Endometrial cancer is diagnosed using certain tests and will depend on your symptoms. These tests can include:

- ultrasound scan - a small scanning device that is inserted into your vagina and scans your womb.
- hysteroscopy - a thin tube with a camera at the end (a hysteroscope) is passed through the vagina and into your uterus to take a biopsy (small tissue sample). Your doctor will then send the biopsy to a lab for testing to find out whether you have endometrial cancer.
- CT scan – a CT scan uses x-rays of your body to create a 3 dimensional (3D) image. You usually have a CT scan to assess your chest, abdomen and pelvis.
- MRI scan – this type of scan uses magnetism and radio waves to take pictures of the inside of the body. This can tell your doctor where the cancer is, the size of the cancer, and whether it has spread to the lymph nodes.

What are the treatment options for endometrial cancer?

Surgery is the most common form of treatment for endometrial cancer. There are a number of different types of surgeries that include removing:

- your uterus and cervix (total hysterectomy (TH))
- both your ovaries, and fallopian tubes (bilateral salpingo-oophorectomy (BSO))
- sentinel lymph node (SLN) sampling around your uterus or in your pelvis

A small number of patients require additional treatment following surgery. This is usually radiotherapy, which can be external or internal.

Chemotherapy is used less commonly to treat endometrial cancer. There are other medicines, such as immunotherapies, to treat endometrial cancer, if required. Immunotherapies can use the immune system to attack cancer cells. Treatment is tailored to each person.

What is ovarian cancer?

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

Ovarian cancer associated with Lynch syndrome can present at an earlier age and stage compared to ovarian cancer in the general population.

Your risk of developing ovarian cancer, and the age at which you may develop it, depends on the gene affected.

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

Lynch syndrome is caused by changes in certain genes, including genes we all have 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 ovarian cancer in your lifetime ranges from 6-13% depending on which gene is affected.

There may be a small increased risk of ovarian cancer in people with changes in the PMS2 gene. However, it is important to take your family history into account.

More information



To find out about your risk of developing ovarian 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.

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

This includes:

- things you can't change, like your family history, age and your genes
- things you can change, like your lifestyle habits.

Things you can't change:

- ageing
- genetic conditions such as Lynch syndrome
- having endometriosis or diabetes
- having started your periods at a young age or gone through a late menopause (over 55)

Things you can change:

- living with overweight or obesity
- smoking tobacco
- avoiding alcohol

How can I reduce my risk of developing ovarian cancer if I have Lynch syndrome?

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 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 may be recommended to have a bilateral salpingo-oophorectomy (BSO) in addition to their total hysterectomy (TH). This will depend on family history or other factors.

What are the symptoms of ovarian cancers associated with Lynch syndrome?

Knowing the symptoms of ovarian cancer can help to find cancer at an early stage. You should contact your doctor without delay if you have one or more of these symptoms:

Symptoms of ovarian cancer include:

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

How are ovarian cancers diagnosed?

Ovarian cancer is diagnosed using certain tests and will depend on your symptoms.

These tests can include:

- blood tests including the CA125 blood test.

- ultrasound scan – a small scanning device that is inserted into your vagina and scans your womb.
- CT scan – a CT scan uses x-rays of your body to create a 3 dimensional (3D) image. You usually have a CT scan to assess your chest, abdomen and pelvis.
- MRI scan – this type of scan uses magnetism and radio waves to take pictures of the inside of the body. This can tell your doctor where the cancer is, the size of the cancer, and whether it has spread to the lymph nodes.

Most ovarian cancers are diagnosed at an advanced stage. It is important that if you have any symptoms of ovarian cancer, that you seek medical advice.

What are the treatment options for ovarian cancers?

Because ovarian cancer is commonly diagnosed at an advanced stage, most patients will undergo more than one treatment approach. Surgery and chemotherapy are the most common types of treatment for ovarian cancer. In some cases, patients with ovarian cancer will receive chemotherapy first, to control and shrink the disease. This is often followed by surgery.

For others, surgery is the first line treatment. Surgery for ovarian cancer involves removing the uterus, cervix, both fallopian tubes and ovaries and any other site of disease, e.g. bowel, appendix, omentum (layer of fat overlying the bowel). In order to identify exactly where disease is a planning laparoscopy, or keyhole surgery, is carried out to prepare for a bigger surgery. Chemotherapy is used at the time of surgery in some cases.

Cancer treatments are always changing and improving. There are now a large number of targeted treatments that are used in ovarian cancer. These are usually given after the initial chemotherapy and surgical treatment.

Can I take Hormone Replacement Therapy (HRT) if my ovaries have been removed?

Before surgery your team will have a conversation with you about how you manage your menopausal symptoms.

HRT may be prescribed by your doctor to help with menopausal symptoms if you have your ovaries removed before menopause. This will depend on your personal cancer history.

It is recommended that women undergoing a total hysterectomy (TH) and a bilateral salpingo-oophorectomy (BSO) consider taking HRT until age 50, or in consultation with their doctor until they wish to stop. This is not a recommendation for women with a diagnosis of breast cancer.

What is a surgical menopause?

Surgical menopause occurs when both your ovaries are removed during surgery before you have gone through a natural menopause. This causes sudden onset of the menopause after surgery.

More information



For further information on early or premature menopause

visit **nhs.uk**
and search for:
'Early or premature menopause'

or **scan the QR code**

What can I do to reduce my risk of endometrial and ovarian cancer?

If you have Lynch syndrome, here are some other things you can do to reduce your risk of gynaecological 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 www.quit.ie 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** 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

Lynch syndrome - continued



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

Cancer - endometrial



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



For more information on womb cancer,
visit **cancer.ie**
and search for: 'womb cancer'
or **scan the QR code**

Further information

Cancer - ovarian



For more information on ovarian cancer,
visit **www2.hse.ie**
and search for: 'ovarian cancer'
or **scan the QR code**



For more information on ovarian cancer,
visit **cancer.ie**
and search for: 'ovarian cancer'
or **scan the QR code**



For more information on ovarian cancer,
visit **ovacome.org.uk**
or **scan the QR code**

Cancer - gynaecological



For more information on gynaecological
cancers in Lynch syndrome,
visit **thisisgo.ie**
or **scan the QR code**

Further information

Cancer - gynaecological continued



For more information on gynaecological cancers

visit [cancerresearchuk.org](https://www.cancerresearchuk.org)

or **scan the QR code**



For more information on gynaecological cancer,

visit [nhs.uk/
conditions/](https://www.nhs.uk/conditions/)

or **scan the QR code**

Cancer - trials



For more information on cancer trials in Ireland,

visit [cancertrials.ie](https://www.cancertrials.ie)

or **scan the QR code**

Further information

Menopause



For more information on menopause you can visit the National Maternity Hospital Complex Menopause Clinic

on **nmh.ie**

or **scan the QR code**

Endometriosis



For more information on endometriosis, visit **www2.hse.ie** and search for: 'endometriosis'

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 leaflet.

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NCCP-COM-088

Gynaecological cancers in Lynch syndrome. Information
for patients and families.

Produced by: **HSE NCCP**
Print date: **December 2025**
Review date: **December 2028**
Product code: **HCC01843**

