



Genetic testing and endometrial cancer

Information for patients from the Gynae Oncology Family History and Genetics Team

This leaflet is for patients diagnosed with endometrial cancer. It explains the following:

- What genetic testing is.
- What genes and gene variants are.
- Whether endometrial cancers are inherited.
- Why you have been referred to the genetics clinic.
- What will happen at your clinic appointment.
- Who you can contact if you have any questions.

We hope this leaflet answers some of the questions you may have. If you have any further questions or concerns, please speak to a member of the genetics team.

What is genetic testing?

Genetic testing is a blood test that looks for inherited changes in genes.

What are genes?

Genes contain our DNA. They are like an instruction manual or code that tell our cells how to function.

We have two copies (pairs) of every gene. We inherit one copy from our mother and one copy from our father.

What is a gene variant?

Sometimes a gene may have a variant (change) that is inherited from one parent or the other.

A gene variant stops a gene from working properly. This means that a person is more at risk of developing endometrial and other cancers.

Are all endometrial cancers inherited?

Womb cancer is the fourth most common cancer in women in the UK. Most diagnoses are due to older age, an unhealthy lifestyle, or being overweight or obese. However, a small number of womb cancer cases are caused by inherited or genetic conditions. One of these conditions is called Lynch Syndrome. [1]

Why have I been referred for genetic testing?

You have been referred for genetic testing to see if you have inherited a gene variant.

If a gene variant is found, it will mean that you have a condition called Lynch Syndrome. Ninety-five out of every 100 people with Lynch Syndrome do not know that they have it [2].

If you find out that you have Lynch Syndrome, you can be offered regular screening. This screening will check for any other cancers that could possibly develop. It may also mean that other family members could be tested.

Where will my appointment take place?

Your clinic appointment will be at one of the East Kent Hospital sites nearest to where you live.

How long will my appointment be?

Please allow up to 45 minutes for your appointment.

Can I bring a friend or family member to my appointment?

Yes. We encourage you to bring a relative or friend with you to your appointment. Not only can they support you, but they can also ask questions that you may not have considered.

We do not advise you to bring children to your appointment.

Do I need to bring anything to my appointment?

Please complete the Family History form that we sent you. Complete this form to the best of your knowledge, and bring it to your appointment. If there is information that you don't know, please don't worry.

What will happen at my appointment?

Your specialist nurse will:

- Ask you questions about your family history.

- Explain about genetic testing.
- Explain why genetic testing is being offered to you.
- Explain how testing may affect other family members.
- Explore the possible disadvantages of having a genetic test.
- Explain the different results that may come back from the test.
- Explain the next steps once your results are back.

Will I need to make a decision now?

No. There will be time for you and any relative or friend to ask questions.

You do not need to decide about having genetic testing on the day. You may need more time to think about this and discuss it with your friends and family. When you are ready, another appointment can be made.

If you decide to go ahead with genetic testing, your specialist nurse will:

- ask you to sign a consent form; and
- take a sample of blood.

What if I have any questions?

If you have any questions or concerns about your appointment, please speak to a member of the team.

- **Gynae Oncology Family History and Genetics Team**
Queen Elizabeth the Queen Mother (QEQM) Hospital
St Peters Road, Margate, Kent CT9 4AN
Telephone: 01227 868666 (Cancer Care Line; open Monday to Friday 9am to 4pm)

Further information

- Macmillan Cancer Support: genetic testing for cancer (<https://www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/causes-and-risk-factors/genetic-testing>)
Telephone: 0808 808 00 00
- The Eve Appeal: Lynch syndrome (<https://eveappeal.org.uk/resource/lynch-syndrome/>)
Telephone: 0808 802 0019

References

1. NHS & RM Partners West London Cancer Alliance. Information for Patients with Endometrial Cancer. (<https://rmpartners.nhs.uk/wp-content/uploads/2021/07/Information-for-Patients-with-Endometrial-Cancer-July-2021.pdf>)

2. NHS England. Life-saving NHS test helping to diagnose thousands with cancer-causing syndrome. 7 April 2023. (<https://www.england.nhs.uk/2023/04/life-saving-nhs-test-helping-to-diagnose-thousands-with-cancer-causing-syndrome/>)

[Websites last accessed 10th September 2025]

What do you think of this leaflet?

We welcome feedback, whether positive or negative, as it helps us to improve our care and services.

If you would like to give us feedback about this leaflet, please fill in our short online survey. Either scan the QR code below, or use the web link. We do not record your personal information, unless you provide contact details and would like to talk to us some more.

Giving feedback about this leaflet



<https://www.smartsurvey.co.uk/s/MDOBU4/>

If you would rather talk to someone instead of filling in a survey, please call the Patient Voice Team.

- **Patient Voice Team**
Telephone: 01227 868605
Email (ekhuft.patientvoice@nhs.net)

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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