



Genetic testing and breast cancer

Information for patients from the Breast Cancer Family History Team

This leaflet is for patients diagnosed with breast cancer. It explains what will happen in the Breast Cancer Family History Clinic.

What is genetic testing?

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

Are all breast cancers inherited?

Most breast cancers (nine in 10) are caused by a combination of chance and the environment (sporadic). As we get older our bodies are less able to protect us from cell changes. These cell changes can lead to the development of cancer.

Only around one in 10 breast cancers are due to an inherited cause.

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 breast cancer.

Why have I been referred for genetic testing?

Your breast team has referred you for genetic testing to see if you have inherited a gene variant. Finding out if there is an inherited cause for your breast cancer will allow your breast team to plan your treatment.

Where will my appointment take place?

Your clinic appointment will be at the Kent and Canterbury Hospital. If you cannot attend the hospital, then the appointment can be offered by telephone or video call.

How long will the 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 bring children to your appointment.

Do I need to bring anything to my appointment?

No. However, your specialist nurse will ask you questions about your family history, such as:

- Who in your mother's and father's family have or have had cancer?
- What type of cancer did they have?
- · What relationship are they to you?
- What age were they diagnosed?
- · Do you have any Jewish ancestry?

You may find it useful to write this information down before your appointment. If you do not know this information, please don't worry.

What will happen at my appointment?

Your specialist nurse will:

- Ask you about your breast cancer treatment plan (don't worry if you don't know this or you are waiting for results).
- · 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.
- Give you written information about genetic testing.

Will I need to make a decision now?

No. There will be time for you and any relative or friend to ask any 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. A further appointment can be made when you are ready.

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

- · Ask you to sign a consent form
- · Arrange a blood test

What if I have any questions?

If you wish to speak to a member of the team before your appointment, please contact the Breast Cancer Family History Team.

• Breast Cancer Family History Team

Kent and Canterbury Hospital, Canterbury

Telephone: 01227 868666

Email (ekh-tr.breastfamilyhistory@nhs.net)

Further information

• Breast Cancer Now (https://breastcancernow.org)

Telephone: 0808 800 6000

Macmillan Cancer Support (https://macmillan.org.uk)

Telephone: 0808 808 0000

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 (ekhtr.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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