BRCA1 predictive testing

This leaflet offers information about predictive testing for someone who has a chance of inheriting a change (mutation) in a gene called BRCA1. If you have any further questions or concerns, please do not hesitate to contact your genetics clinician.

What are genes?

Genes are coded messages that give instructions for how cells in the body grow and function. Genes come in pairs; we inherit one copy from each parent. Genetic testing has shown that a change (mutation) in a gene called BRCA1 is present in your family.

How is the BRCA1 gene inherited?

Someone with a BRCA1 gene mutation (called a BRCA1 carrier) also has one normal copy of the BRCA1 gene. Only one copy of each gene pair is passed on to a child. If someone has a BRCA1 gene mutation, they have a one in two (50%) chance of passing on this mutation to each child they have, regardless of their gender or the child's gender.

How are genes involved in inherited breast cancer and ovarian cancer?

The BRCA genes protect us by controlling the growth of cells. If a woman inherits a mutation in one copy of a BRCA gene pair, they will be susceptible to breast and ovarian cancer. Then, if the second copy of the pair also becomes faulty, cancer (uncontrolled cell growth) can develop.

What is a predictive genetic test for BRCA1?

If you know that someone in your family is a BRCA1 carrier, there is a genetic test you can have to see if you have inherited the same mutation. We call this a predictive test. It involves taking a blood sample.

Before we offer you a predictive test we will discuss with you what the test could mean for you and your family. We will give you the opportunity to ask questions. Your genetics clinician will have helped you to consider:

- how this test result could affect you and your future
- who you plan to talk to about this test and result
- who you would like us to share your result with
- how this test could affect your family, children and relationships
- if this could affect your employment or insurance
- how you will adjust to your result.

After we have taken a blood sample and have the familial mutation report, the results of a predictive BRCA gene test take four to six weeks to be processed. Once the result is ready, you will be notified and offered further appointments, if appropriate.

What are the possible results of predictive BRCA1 genetic testing?

1. You have not inherited the mutation in the BRCA1 gene.

- Although there is an inherited tendency to get breast or ovarian cancer in your family, you have not inherited it.
- This means your own risks of developing BRCA1-related cancers are not increased.
- As you do not have the BRCA1 gene mutation, you cannot pass it on to your children.

2. You have inherited the BRCA1 gene mutation.

- If you are a woman, you have an increased risk of breast cancer and ovarian cancer.
- For women in the general population, the 'lifetime risk' of breast cancer (the chance of getting it at some point in life) is one in eight. For you, this lifetime risk is up to seven in 10 (or 70%). In the general population, the lifetime risk of ovarian cancer is one in 50 (or 2%). For you, this lifetime risk is up to 45%.
- If you have already had a breast cancer, you have up to a 65% chance of developing a second primary breast cancer.
- There are a number of options available to manage this risk; your genetics clinician will discuss these in detail with you to work out what the best options are:
  - yearly scans to check for breast cancer, from the age of 30 (unfortunately no reliable checks for ovarian cancer are currently available)
  - having a risk-reducing mastectomy (removal of breast tissue) and reconstruction
  - having risk-reducing removal of both ovaries and fallopian tubes (the tubes that connect the ovaries and the womb), around the age of 35-40
  - staying aware of the symptoms of breast and ovarian cancers, and being generally vigilant about your body so you can report any concerning symptoms to your GP.
- If you are a man, you have a minimally increased lifetime risk of developing prostate cancer. This risk does not require any additional clinical screening.

Things to consider

Deciding to have predictive genetic testing can be a difficult and complex process. You may wish to consider the points below before testing.

- **Timing.** Why now? Will it change your immediate treatment? What other challenging events are happening in your life?
- **Psychological impact of knowing.** How you would feel if a BRCA mutation was identified and how would you share this information within the family?
- **Assessing your own coping strategies.** How have you dealt with difficult situations in the past? What strategies do you use to help you deal with difficult news?
- **Next steps.** What measures might you consider taking to address your risks of breast and ovarian cancer if we find that you have a gene mutation?

There are no right or wrong answers to these questions, but it is best to consider now what the answers may be, so that when you have your result you have an idea of how you may proceed.

Support

Undergoing predictive genetic testing and receiving the results can be a challenging time. Some people may wish to talk through their feelings, coping strategies and other issues before making a decision, or after receiving their result. Several avenues of support are available to BRCA1 carriers, including the following:

- your genetics clinician
- the HBOC family service (see below)
- the BRCA patient support groups
- clinical psychologist
- your GP
- cancer charities such as Breast Cancer Now (Someone Like Me service) and Macmillan.

Your genetics clinician will discuss these with you in more detail so you can work out what the best sources of support will be.

The hereditary breast and ovarian cancer (HBOC) family service

BRCA1 carriers are invited to our HBOC family service clinic. There, you will be able to ask questions and discuss your management in detail with a team of specialists. If we find you have the mutation, we will send you your invitation, a leaflet about this service, and a psychological questionnaire with your test result.

Research studies

Regardless of the result of your testing, there may be an opportunity for you to take part in research. Your genetics clinician or a research nurse will discuss this with you. For further information, contact a member of the research team on **t:** 020 7188 2603.

Useful sources of information

Breast Cancer Now
UK-wide charity providing care, information and support to people affected by breast cancer.
t: 0808 800 6000 (helpline, Monday-Friday 9am-4pm, Saturday 9am-1pm)
e: info@breastcancernow.org **w:** https://breastcancernow.org

Someone Like Me
Service provided by Breast Cancer Now. Puts you in touch with a trained volunteer who has (or has had) primary breast cancer, or is undergoing genetic testing, for advice and support.
t: 0345 077 1893 **w:** https://breastcancernow.org/information-support/support-you/someone-me-email-support

Macmillan Cancer Support
Support and advice charity for people affected by cancer.
t: 0808 808 0000 (Monday-Friday, 9am-8pm) **w:** www.macmillan.org.uk

Contact us

If you have any questions or concerns about anything in this leaflet, please contact your genetics clinician on **t:** 020 7188 1364 (Monday to Friday, 9am-5pm).

Guy's and St Thomas' hospitals offer a range of cancer-related information leaflets for patients and carers, available at www.guysandstthomas.nhs.uk/cancer-leaflets. For information leaflets on other conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.guysandstthomas.nhs.uk/leaflets

Dimbleby Cancer Care provides cancer support services for Guy's and St Thomas'. We have a drop-in information area staffed by specialist nurses and offer complementary therapies, psychological support and benefits advice for patients and carers.

Dimbleby Cancer Care is located in the Welcome Village of the Cancer Centre at Guy's, **t:** 020 7188 5918 **e:** DimblebyCancerCare@gstt.nhs.uk

Pharmacy Medicines Helpline
If you have any questions or concerns about your medicines, please speak to the clinical nurse specialist or other member of staff caring for you or call our helpline.
t: 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111 **w:** 111.nhs.uk

NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.
w: www.nhs.uk

Was this leaflet useful?
We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

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A list of sources is available on request

Guy's and St Thomas' NHS Foundation Trust

Our values: Put patients first | Take pride in what we do | Respect others | Strive to be the best | Act with integrity