



**Birmingham Women's
and Children's**
NHS Foundation Trust

Information leaflet for people who
have been referred to the cancer
genetics service

The Cancer Genetics Service



By your side

We know there is a lot of information in this leaflet. You may find it helpful to keep it and refer back to the relevant sections later.

Why have I been referred?

You or some of your relatives may have had cancer. The Genetics Service can help answer some of the following questions:

- Are members of my family at an increased risk of developing cancer?
- Can we have extra cancer screening?
- Is there anything I can do to reduce my cancer risk?
- Can I have a genetic test?

What is the family history form for?

To answer these questions accurately, we need to make a full assessment of your family history. It is important for us to have as much information as possible to do this so we ask you to complete the family history form. If it is not possible to gather all this information, we can proceed with whatever information you can give us.

I've completed the form, what happens now?

We try and confirm details of your relatives' cancers, where possible. We need permission from relatives who are living to look at their medical records. Once we have received your family history form, we will send consent forms for the appropriate relatives.

We can send these to them directly or via you if you would prefer. Once we have the information we need, we will contact you again with advice. In the meantime, if you have any concerns about symptoms you should consult your GP.

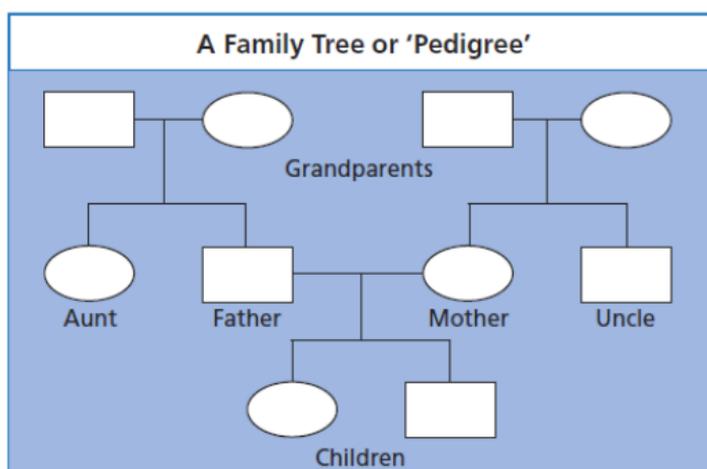
How long will all this take?

To an extent, this depends on you and your family. We really need to receive information as promptly as possible to advise you quickly and accurately. Once we have received your family history form, we aim to contact you with screening advice or to see you in clinic within 18 weeks. This is in line with government targets.

If the consent forms are delayed, we may not be able to obtain all the information we need in time. This may affect the accuracy of our advice. If there is a particular problem with this time frame please do let us know so we can postpone our advice. If the delay needs to be longer than 6 months, you may prefer to be re-referred at a more appropriate time.

How is my family history assessed?

From the form, we will draw your family tree.



We may also ask you to get permission from a Cancer is common, particularly in older people. Most of these cancers will have occurred by chance. From your family tree, we look at the types of cancer in your family and the ages of diagnosis.

Only a small number of families have a strong inherited tendency to cancer. This is more likely when we see: Several relatives with the same types of cancer, or cancers which are associated (e.g. breast and ovary or bowel and womb), Individuals with cancer at young ages, Individuals with more than one primary cancer.

Certain cancers (e.g. lung and cervical) have recognised environmental causes and tend not to be inherited.

What happens next?

Once we have assessed your family history we will write to you about your risk and any appropriate cancer screening. We may also suggest an appointment to discuss this further, in which case we will ask you to call our

booking line to arrange an appropriate time and date.

Not everyone is routinely offered an appointment in the Genetics clinic. However, if you still have questions after receiving our letter we are happy to discuss your concerns over the telephone or to arrange an appointment for you if you wish.

What would the appointment involve?

You would see one of our doctors or genetic counsellors. The appointment will usually be at one of your local hospitals. Consultations last around 45 minutes. You are welcome to bring members of your family or a friend to the clinic.

If you need an interpreter, please let us know in advance so we can make the appropriate arrangements.

What about screening?

Cancer screening aims to detect cancers early. Treatment for early cancers is usually more effective. However, all types of cancer screening have drawbacks. It is important that extra screening is only offered when the benefits to an individual outweigh the risks.

Can I have a Genetic Test?

Genetic testing is only possible in a small number of families. In these families we usually require a blood sample from a relative with cancer before testing can be considered in other family members. Some conditions may need more than one appointment before a blood sample is taken for genetic testing especially if having a predictive test.

Predictive testing is when you are considering being tested for a condition previously diagnosed in your family that may develop in the future. Before any procedure or test is carried out you must give your permission. This is giving your consent.

DNA Banking

If a genetic test is not available for your family at the moment, we may offer to store a blood sample from a family member with cancer in case of future medical advances.

If a relative with cancer is terminally ill it is important for you to let us know as soon as possible. It may be appropriate to arrange for a blood sample to be stored from your relative. In this way we can increase the possibility of genetic testing in the future without causing undue distress to your relative.

Research Studies

We may let you know if there are approved research studies around inherited cancer which you or your family could take part in. It is your decision whether you wish to take part in these studies and it will not affect your care if you choose not to.

What about other relatives?

Relatives who are concerned about their own risk of developing cancer should ask their GP to refer them to their local Cancer Genetics Service. We can only share the information on your family with your permission.

What happens to my information?

Your information may need to be shared with other medical professionals involved in your care, this will be discussed with you at your appointment. Some of your information maybe used for clinical audit, training/educating staff and, with your consent, for approved health research. This ensures that the quality of patient care is sustained, and improved. If you would like to find out more about how your information is used, please refer to the leaflet "Your Information: A guide to why the NHS collects information about you and how it is used" available on the Trust website at:

<http://www.bwhct.nhs.uk/information-and-leaflets/generalinformation>

Where can I get further information?

Some information about cancer can be found on the following websites. You may wish to wait until after your appointment so that we can direct you to information most appropriate to you.

<http://www.cancerresearchuk.org/>
<http://www.macmillan.org.uk/Home.aspx>

A copy of the Trust Welcome booklet is available at:

<http://www.bwhct.nhs.uk/information-and-leaflets/general-information>

You will also find information here on how to provide compliments, suggestions and complaints

Telephone: 0121 335 8024
Email: genetics.info@nhs.net

**Birmingham Women's and Children's
NHS Foundation Trust**
Mindelsohn Way, Edgbaston
Birmingham B15 2TG

Author: Clinical genetics Unit
Reviewed date: February 2016
Next review: February 2019
Ref No: CG1

