

Your appointment in Clinical Genetics

Leicester Clinical Genetics Service

Information for Patients

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This leaflet should help to explain what to expect at your clinical genetics appointment.

The Leicester Clinical Genetics Service is a specialised department within Leicester's Hospitals. Our service helps families who have a known or possible inherited disorder. This includes diagnosis, management and genetic counselling. We may also be involved in giving advice about medical care.

Why have I been offered an appointment?

There are lots of reasons why someone might need the help of the Clinical Genetics Service. Here are some of them:

- A known genetic condition runs in your family and you may be concerned about your chances of developing the condition. You may also be concerned about the possibility of passing on this condition to your children and future generations.
- Your child has several clinical problems that together might point to a possible genetic cause.
- You or your partner is pregnant and there is a 'finding' on an antenatal scan / result, or you have a family history of a genetic condition. Also if you, your partner or your family have had a number of pregnancy losses.
- You have a family history of particular types of cancer, where more information and sometimes testing, can be helpful in deciding what to do next (such as screening advice).

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

When you visit us, you may meet:

- A Clinical Geneticist, or Trainee Geneticist.
This is a doctor who has experience of a wide range of genetic conditions.
- A Genetic Counsellor, or Trainee Genetic Counsellor.
This is a professional with specialist training in genetics and counselling skills.

What happens before the appointment?

If your referral is related to a history of cancer, we will send you a 'Family History Questionnaire' before your appointment. In other cases, our Administrator or Genetic Counsellor will phone you for information about your family history.

We use this information to draw up your family tree and check whether we need any additional information before your appointment. This helps us provide the best advice for you when you are seen in clinic.

Sometimes, we can find out all the information we need about your family history from you. Other times, we may ask you to pass on consent forms to your relatives for their permission to access their records for information that could be relevant to you.

What happens during the appointment?

Most appointments last between 45 minutes and 1 hour, as we cover a lot of information.

We will talk to you about your family history in detail.

We may also need to examine you, take photographs and sometimes send blood samples for genetic testing.

Please bring your child's red book (if under 5 years old) for their assessment.

If you are referred with another relative, we may not see you together (please contact us if you wish to discuss these arrangements).

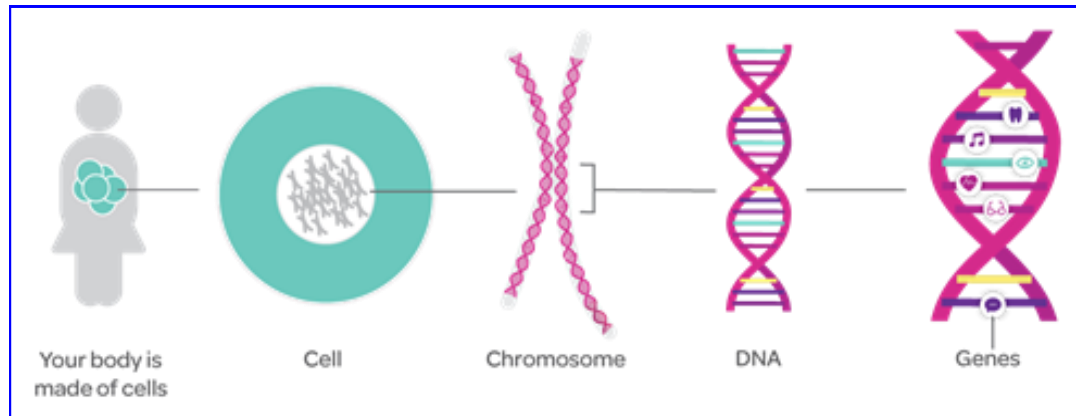
What is genetic counselling?

Genetic counselling is the process of giving you information; answering questions and listening to your concerns. It also helps you to understand any information given to you during your appointments, and how genetic conditions might be managed.

What is genetic testing?

Genetic testing may help confirm a diagnosis, or predict whether you have inherited the genetic condition that is in your family.

Genetic testing isn't offered to everyone and we can talk about what you can be offered at your appointment.



This picture shows how genetic information is packaged within each cell of our body.

We will discuss this in more detail with you in clinic.

Ref: <https://images.app.goo.gl/PneN7MnBuyZFK4Tb8>

We aim to help you and your family by:

- making, confirming or excluding a diagnosis.
- providing information about a condition in a way that is easy to understand.
- discussing what the effect of a condition might be in the future.
- discussing the possibility that the condition may also affect future children and other family members.
- explaining types of testing or screening available, especially in relation to certain cancers.
- if available, provide contact details for any support groups or other organisations that can give you more advice.

Research and teaching

Leicester's Hospitals are often involved in medical teaching and research. At your appointment we may talk to you about research that is relevant to you or your family. Taking part in any research study would be an optional extra to the care we will be giving you. It is your choice on whether you wish to take part.

As we are a teaching hospital, there may be other healthcare professionals or students on placement in our Department. We will check if you are happy to have students present at your appointment.

If you cannot attend your appointment

Please cancel your appointment in good time. We have long waiting lists for our appointments, so please let us know as soon as possible, so we can offer the appointment to someone else.

Please note: anyone who fails to attend an appointment or who cancels more than once will be discharged back to their referring clinician, as per Trust guidelines. However, you may ask them for another referral to our service, if you still wish to be seen.

If you have any questions

If you need more information about your referral to Clinical Genetics, please contact us on:

Clinic Co-ordinators: 0116 258 5736

Administration Team: 0116 258 5697

Further information

Our page on the hospital website is here:

<https://www.leicestershospitals.nhs.uk/aboutus/departments-services/clinical-genetics/>

Further information may also be available from:

Genetic Alliance UK Support Group: www.geneticalliance.org.uk/

Phone: +44 (0)20 7831 0883 / Email: contactus@geneticalliance.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk