

medicine it is not yet possible to offer genetic testing for all conditions.

What if I cannot attend my appointment?

As only three or four families are seen in each clinic session, it is important that we don't waste any appointments. **Please let us know well in advance if you will be unable to attend so that this appointment can be offered to another family.** You will then be given an appointment when one is next available. Please be aware that if you cancel several consecutive appointments it may be necessary for you to be re-referred if you still wish to be seen.

It is our hospital's policy not to send you a further appointment if you do not attend and have not let us know beforehand.

If you have decided that you do not wish to continue with genetic counselling at this time please let us know and we won't send you any further appointments.

What happens next?

After the appointment the genetic counsellor or doctor will write to you summarising the information you have been given.

Usually only one clinic appointment is needed. However, some people may need to be seen again to discuss results or for follow up. If there are further developments in the future we may offer you another appointment.

We may also offer to see other family members if appropriate.

Sometimes referral to other specialist services is needed and your genetic counsellor or doctor will discuss this with you.

Where can I get further information?

Some information about genetic conditions can be found on the internet. However, we would recommend that you wait until after your appointment so that we can recommend reliable sites appropriate to you.

If you need further information or advice please contact:

Clinical Genetics Unit
Birmingham Women's Hospital
Metchley Park Road
Edgbaston,
Birmingham
B15 2TG

Telephone: 0121 627 2630

Fax: 0121 627 2618

Email: ClinicalGenetics.info@bwhct.nhs.uk

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

West Midlands Regional Clinical Genetics Service

*Information about your
referral to the clinical
genetics service*



This leaflet aims to provide a brief guide to the help and advice that the Clinical Genetics Service can give you.

What is genetics?

Genetics is the study of the way in which we share some features within our family, such as hair or eye colour and how we pass some of these on to our children. Sometimes conditions which can affect our health are also passed on in our genes. Clinical Genetics looks at how these inherited conditions are passed on in families.

What does the Clinical Genetics Service do?

Doctors and genetic counsellors give people information about these conditions and how they are inherited. We discuss:

- the diagnosis, cause and treatment of genetic disorders.
- how likely they are to happen in a family.
- the choices members of the family have.
- the possible effects on the family and support available.
- options regarding pregnancy and reproduction.

We aim to give information which may help you to make decisions but we will not tell you what to do.

Why have I been referred?

Some people are referred because our specialist doctors may be useful in trying to make a diagnosis in their family. We also see families to discuss the implications of a genetic condition which is already known to run in the family.

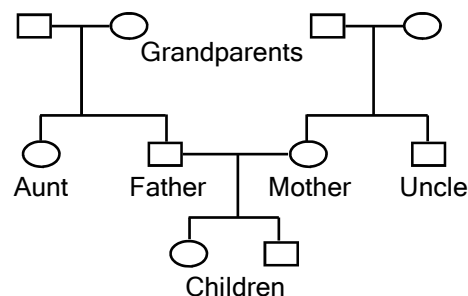
What happens once I have been referred to the clinical genetics service?

A genetic counsellor may arrange to see you at home or in a genetics clinic local to you. **Please let us know** if the date or time is not convenient so that other arrangements can be made.

Alternatively you may be contacted by telephone so please make sure you provide an appropriate daytime telephone number.

The genetic counsellor can answer your questions about the genetic service and will ask you about your family so that a family tree can be drawn. Sometimes it is possible for your genetic counsellor to answer all of your questions but it may be necessary to have an additional appointment with the genetics doctor.

A Family Tree or 'Pedigree'



Your genetic counsellor may ask you about:

- full names of family members
- dates of birth (if possible)
- information about pregnancies and health problems within the family.

We may also ask you to contact a relative to get permission

for us to obtain further medical information about their condition. *We will never contact a relative or obtain medical records without permission.*

What happens if I need to see a genetics doctor?

If it is not clear whether there is a genetic condition in your family, it is likely that you will need to see a genetics doctor. They will review the information from your medical records and the genetic counsellor appointment. Sometimes the doctor will need to examine you. They will then assess how likely it is that there is an inherited condition in your family and spend some time discussing your particular concerns.

Your appointments will usually be at your nearest hospital where a genetics clinic is held. For some specialist clinics you may need to travel further.

Consultations last between 30 and 45 minutes. If you would like to bring members of your family or a friend to the clinic, we would be very pleased to see them with you.

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

Will I need any tests?

We may need to take a blood sample at your appointment if any genetic testing can be offered.

If this, or other tests are needed, we will discuss this with you, ask for your consent and then make the arrangements.

As genetics is a developing branch of