

**This leaflet aims to answer some common questions asked by people when they have been referred to the genetic clinic.**

If you, or someone in your family, is thought to have a genetic condition you may have lots of questions but are unsure who to approach. People often ask us questions such as:

- ❖ Why have I been referred?
- ❖ What has happened?
- ❖ Why has it happened?
- ❖ How will it affect me?
- ❖ Could it happen again?
- ❖ How will it affect my family?
- ❖ Are there any tests?

Other families have questions related to pregnancy.

The Clinical Genetics Service is a NHS service that tries to answer your questions. We are based at Sheffield Children's Hospital, but we do see people of any age. We also hold clinics in Worksop, Doncaster, Buxton, Rotherham, Barnsley, Chesterfield and Grimsby.

### **What does the Clinical Genetics Service do?**

We aim to provide accurate and up-to-date information about inherited conditions for you, your family and your doctor. Some of this information may be new to you.

A team of genetic nurses/counsellors and doctors are able to talk through this information and help you to understand what is relevant.

Talking about the condition and the medical and social support available can be useful.

Staff are also available to help you reach decisions about things like:

- ❖ Whether or not to have a genetic test (if this is available)
- ❖ The choices available to you if planning a pregnancy
- ❖ What to tell your children and/or other relatives

This whole process is sometimes called "genetic counselling"

**Our aim is to give information that you may find helpful to make your own decisions. We will not tell you what we think you should or should not do.**

### **What happens next?**

Depending on your situation a genetic nurse/counsellor will either:

- ❖ Arrange to visit you at home
- ❖ Talk with you on the telephone
- ❖ Arrange an appointment for you to come straight to clinic

The home visit and telephone discussion allow us to ask you for details about your family. This helps us to give you accurate information in clinic. It also gives you the opportunity to talk about any concerns you have before you come to clinic.

After the home visit or telephone call, you will usually be offered a clinic appointment in your local hospital.

In some situations it is possible to cover everything at the home visit and a clinic appointment may not be needed.

## Who should attend the clinic appointment?

You may bring anyone you wish to clinic. If the referral is for a child, please bring that child along with you, and any other children you may have with similar problems.

Most clinic appointments last between 30 and 45 minutes. This allows time for you to ask us questions. The doctor will sometimes need to examine you or your child/children.

If it is not possible to answer all of your questions at a single appointment, we will make further arrangements with you.

Sometimes a doctor or nurse in training may request to sit in the clinic as an observer. If you do not wish them to be present, please say so. This will not affect the standard of care you receive from us.

**If you need any additional assistance such as transport or an interpreter, please let us know and we will try to arrange it for you.**

**PLEASE LET US KNOW IF YOU CANNOT ATTEND AN APPOINTMENT BY CONTACTING THE APPOINTMENTS CLERK ON:**

**0114 271 7027**

## What will happen afterwards?

Following your visit to clinic you will usually be sent a letter that summarises what has been discussed. We will also write to your GP and any other specialists who are looking after you.

You may be invited to participate in research projects. This will be independent of the care you receive from our team within the NHS and you are not obliged to take part.

### Confidentiality

As with any other medical consultation, your information will be treated in strictest confidence. We will not discuss your details with other family members without your consent.

We often need access to relatives' medical records. If we have to do this we will ask for their consent (if they are alive) with your agreement.

We will not release information to anyone else (including insurance companies) without the written consent of the person involved.

The discussion we have with you may have implications for other family members. In some situations you may wish to share your genetic information with others in your family. We will help you to do this.



Sheffield Children's  
NHS Trust

## Sheffield Clinical Genetics Service

### Your questions answered

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