

The Genetic Clinic

What is genetic counselling?

Genetic counselling is a branch of medicine which specialises in conditions which can affect people in different generations of the same family. These are inherited or genetic conditions.

Who needs genetic counselling?

People who are concerned that a condition in their family may be genetic will probably find an appointment helpful. People who would like further information on a genetic condition in their family will probably find an appointment helpful.

Others who may be referred to the genetic clinic include:

- couples who have had miscarriages or stillbirths.
- people who have had a baby who died not long after birth.
- children whose development is slow.
- children who have a genetic or undiagnosed medical condition.

Before your appointment

It can sometimes be helpful for the genetic clinic to have medical details about other people in your family. You may find a form enclosed, requesting these details. However, we understand that such details are not always available. We will never approach a relative without your permission.

If you are concerned about a medical condition in a relative who will not be present, it can be helpful for you to bring a photograph of this relative with you to the clinic. If the appointment is for a child who may have a genetic condition, early photographs of the child and parents can be useful.

What will happen at my appointment?

The genetic clinic has specialist doctors, nurses and genetic counsellors who aim to provide you with accurate and up-to-date information.

Appointments usually last for approximately 45 minutes. During this time your concerns will be discussed and time will be spent drawing your family tree. You may want to know what your chance is of either inheriting or passing on a genetic condition. You might have questions about tests that are available to confirm a diagnosis, or tests that can be offered during a pregnancy. All these issues will be discussed in understandable terms.

Will I have any tests done at my appointment?

Sometimes we may need to take a blood sample, but it is unlikely that we will do any other tests at your first visit. If we feel that further tests will be useful, these will be discussed with you and arranged with your consent.

Where will I be seen?

The genetic service holds clinics at several different hospitals. We will usually arrange to see you at the clinic nearest your home.

If you need any additional assistance, such as an interpreter, please let us know in advance, and we will try to arrange this.

How will I remember everything?

Following your appointment you will receive a letter in English summarising the topics covered in the clinic. The clinic also has some information available in [*insert language*] which will be offered to you if suitable or appropriate

Finally ...

Many people who come for genetic counselling will feel reassured when they leave. Others will be left with difficult decisions to make. These may include whether or not to have a particular test, or what to tell children or other relatives.

We hope to give you information which will help with these decisions. We will not tell you what you should or should not do. However, we are available to offer help and support by discussing all the options with you.

Come prepared with your questions and concerns. Write them down, if you wish, and we will try to answer them for you.

Thank you for reading this information and we look forward to meeting you.

Glossary (difficult words and their meanings): The Genetic Clinic

This glossary is intended only to explain terms used in the information: The Genetic Clinic. Words shown in **bold** are defined elsewhere in the glossary.

family tree. A diagram to show the people in your family who do and do not have the **genetic** condition, and how they are related to you and to each other .

gene. Information needed for the body to work, stored in a chemical form on **chromosomes**. Changes in genes alter the information and this can change how the body works. Most genes are in pairs, one from the mother and one from the father. (As an analogy: a gene is like a story in a book, changes in genes are like changes in a story).

genetic. Caused by **genes**, concerning **genes**.

genetic counselling. Information and support for people who have a history of a genetic condition in their family, or who are concerned about their risk for inheriting or passing on a genetic condition.

genetic counsellor. A specialist who gives information and support to people who have a history of a genetic condition in their family, or who are concerned about their risk for inheriting or passing on a genetic condition.

miscarriage. Early end to a pregnancy, before the baby can survive outside the womb.

stillbirth. A baby which is born dead.

This glossary is intended only for use by patients and families, with the genetic information to which it refers.

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