

Genetic Counselling

Information Guide

Introduction

Genetic counselling is a quite new branch of medicine, and many people don't know what it involves. This leaflet explains generally what to expect at a genetic counselling appointment.

What is genetic counselling all about?

Some conditions run in families. Genetic counsellors can give people information about these conditions, how they are inherited and how they are likely to happen in a family. If appropriate, we can also discuss the medical management of a disorder and what choices members of the family have in facing the situation.

Who needs genetic counselling?

Anyone who has questions about a condition which they think may be inherited. Some people may want information just for their own peace of mind. Many want to know their own chance of either inheriting or passing on conditions.

Some of the reasons for being referred include:

- A condition that runs in your family or your partner's family.
- You or your partner already have a child with a physical or developmental problem.
- You or your partner have a condition that might be passed on to your children.
- You or your partner have experienced problems with pregnancy loss.
- Particular types of cancer have occurred in several close relatives.

How can genetic counselling help me?

There are several ways the **clinical geneticist** (doctor) and genetic counsellor can help to answer your concerns. Some of these are:

- Making or confirming a diagnosis.
- Providing information about the condition and how it is inherited.
- Discussing the chances that you may be affected by the condition in the future.
- Discussing the chances that future children may be affected with the condition if it already occurs in your family.
- Explaining the types of tests available.
- Talking about ways of coping with the condition and the medical and social support available.

Not everyone who comes to our clinic has a genetic condition.

Will I be given advice?

Genetic counselling can help you make well informed decisions for the future. Many people assume that the doctor will tell or advise them what to do when faced with difficult decisions. Instead, we concentrate on providing information and discussing options to help people make the best decisions for themselves.

Please bring any questions or concerns with you to your appointment – feel free to write them down if you wish.

What will happen first?

The genetic counsellor will usually contact you to arrange a visit at home or will talk with you on the telephone (sometimes, however, we arrange an appointment for you to come straight up to clinic).

This visit or phone call provides an opportunity to obtain details about your family and to draw a family tree. This helps us to give you accurate information in clinic. It also gives you time to talk about any concerns you have before you come to clinic.

After the visit or phone call, you will receive your clinic appointment letter to see a genetic counsellor or clinical geneticist (doctor).

If you need an interpreter, please let us know. We can provide one for both the home visit and the clinic.

What family details are helpful?

For as many close relatives as possible and for any other affected people in your family, it is helpful for us to know:

- Their full name.
- Their date of birth.
- Their address.
- Their GP's name and address.

If appropriate:

- The diagnosis they were given.
- When and where they were diagnosed or treated.

We will not ask for any medical records for any relative without permission. We will also not contact any of your relatives unless you specifically ask us to do so.

What will happen when I come to clinic?

Please check your appointment letter for the location of the clinic. Your partner or another relative or friend is welcome to come with you. The clinical geneticist and/or genetic counsellor will discuss your concerns with you.

They will check the family details you discussed with the genetic counsellor before the clinic. If appropriate, the doctor may want to examine you. Sometimes it is necessary for the doctor to gather more information and/or arrange tests.

When there is a genetic condition in the family, the doctor and/or genetic counsellor will try and help you understand the facts in everyday, common sense terms. They will also discuss the choices that are open to you.

To allow plenty of time for this, each clinic appointment is at least half an hour.

If you are unable to come, it is therefore very important that you let us know as soon as possible so that we can give the appointment to someone else.

Please phone us on 0161 276 6506 if you cannot come to your appointment.

What will happen afterwards?

You may be offered a follow-up appointment. You will also be sent a letter to summarise what has been discussed. If you agree, we will send a copy of this to your GP and any other specialists who are looking after you.

For additional information or support

If you have any further questions about any aspect of genetic counselling, please contact:

Genetic Medicine

6th Floor, St Mary's Hospital, Oxford Road, Manchester M13 9WL

Telephone 0161 276 6506

Fax 0161 276 6145

Department staffed Monday–Friday, 9.00am to 5.00pm.

Do you have difficulty speaking or understanding English ?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

તમે ભાષા કારણે વાતચીત કરવામાં મુશ્કેલી આવે છે ? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

هل لديك مشاكل في فهم اوالتكلم باللغة الانجليزية ؟ (ARABIC)

你有困難講英語或明白英語嗎？ (CANTONESE)

کیا آپ کو انگریزی سمجھنے اور سمجھانے میں دقت پیش آتی ہے؟ (URDU)

Telephone 0161 276 6202 / 6342

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio, British Sign Language video/DVD) or in another language.