



The Trust has a Patient Advice and Liaison Service (PALS) who can be contacted on (0161) 276 8686 and via e-mail: pals@cmft.nhs.uk. They will help you if you have a concern, want advice or wish to make a comment or complaint.

Information leaflets about the service are readily available throughout the Trust. Please ask any member of staff for a copy.

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.

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 specialists that you see.

Further information:

If you need more advice about any aspect of genetic counselling, you are welcome to contact: **Genetic Medicine**, Sixth Floor, Saint Mary's Hospital, Oxford Road, Manchester M13 9WL

Telephone: 0161 901 1845/1847 (Reception)

Facsimile: 0161 276 6145

www.mangen.co.uk

Department staffed

Monday – Friday 8.30am to 5.00pm

We would like to acknowledge our Clinical Genetics colleagues at Guy's and St Thomas' Hospital NHS Trust who designed and wrote the original version of this leaflet.

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.

No smoking policy

The NHS has a responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service

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 કાચી વાતચીત કરવામાં મુશ્કેલી આવે છે? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਨਾਂ ਸਮਝਣ ਵਿਚ ਟਿਕੜ ਹੈ? (PUNJABI)

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

هل لديك مشاكل في فهم أو التكلم باللغة الإنجليزية? (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)

☎ 0161 276 6202/6342

Seen in clinic by:

_____ (Doctor)

and:

_____ (Genetic Counsellor)

Telephone number: _____

© Copyright to Central Manchester University Hospitals NHS Foundation Trust

Regional Genetics Service

Genetic Counselling

Information Leaflet

Please phone if you cannot come to your appointment
0161 901 1845/1847

This leaflet explains what to expect at a genetic counselling appointment.

What is genetic counselling?

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

What family details are helpful?

To give you the most accurate information in clinic, we will need to ask you for details about your family history and to draw your family tree. **Please come to your appointment with as much of the following information as you can gather in advance.**

However, please do not worry if the information available to you is limited.

For as many close relatives as possible and for any other affected people in your family:

- Their full name
- Their date of birth
- Their 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 their permission. We will also not contact any of your relatives unless you specifically ask us to do so.

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. **Not everybody who comes to our clinic has a genetic condition.**

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

What will happen when I come to clinic?

You will receive an appointment to come to clinic at Saint Mary's Hospital or when we hold a clinic in a district hospital in the North-West: please check your appointment

letter. Your partner or another relative or friend is welcome to come with you.

Sometimes the genetic counsellor will contact you before the appointment, usually on the telephone or occasionally by visiting you at home. This contact helps us to collect family details from you in advance and also gives you time to talk about any concerns you have. If we have not contacted you before your appointment and you have any questions, you are welcome to contact us instead on 0161 276 6506.

If you need an interpreter or any type of communication support, please let us know. In the appointment, the clinical geneticist and/or genetic counsellor will discuss your concerns and check your family history details with you. If appropriate, the doctor may want to examine you.

Sometimes they may need to gather more information and/or arrange tests.

When there is a genetic condition in the family or the possibility of an inherited condition, they 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.

Suggestions, concerns and complaints

If you wish to make a comment, have a concern or want to complain, it is best in the first instance to speak to the manager of the ward or department involved.