



Cleft Department

This transition leaflet is part of a series aimed at young people and is produced by the North West Cleft Lip and Palate Network.



You must always discuss your treatment with the appropriate member of staff. Do not rely on this leaflet alone for information about your treatment. This information can be made available in other languages and formats if requested.

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Why is genetics important?

Genes are the instructions that tell the body how to build itself. Lots of different genes are needed to build a human being. Sometimes, when genes have changes in them, a person can be born with a cleft. Sometimes these gene changes are passed through families and from parent to child.

At other times the gene change starts for the first time in a person. Some people with gene changes have other medical problems when they are born, as well as a cleft.

Will my own children have a cleft?

It is possible that if you have a cleft, your children might have one too. To discuss this in more detail and for information about how likely this is, you should ask for a clinical genetics appointment.

What happens at a clinical genetics appointment?

You will be seen in the genetics clinic by a clinical geneticist. depending upon where you live this might be at another hospital.

Clinical geneticists are doctors who are specially trained in looking after patients and families who have, or might develop, conditions caused by changes in genes.

It is their job is to see whether a person only has a cleft or if the cleft is part of another condition. This helps us understand why you have a cleft. It can also tell how likely it might be that other people in your family could have a cleft.

The clinical geneticist will ask you questions such as:

- How was your cleft found?
- How old were you?
- What sort of medical problems and operations have you had?

They will also ask you about other people in the family to see if anyone else had a cleft or has any medical problems and draw out your family tree. They will also look at your mouth and teeth, face, hands, feet and perhaps other parts of your body to see if there any clues to suggest any other medical condition.

You can then talk a bit about genes and how this might be related to why you had your cleft. The clinical geneticist will then tell you how likely it is that other members of the family, including any children you may have in the future, could be born with a cleft. They may talk to you about any special tests or scans that might be helpful.

They may also discuss any options that might be available if you are planning on having a family and children of your own. You will get a letter written to you personally after your appointment, so don't worry if you forget things!

When should I go to clinical genetics?

There is no set time in your life that you should be seen in clinical genetics. You do not have to have a genetics appointment if you don't want to. However you may want an appointment to discuss your personal and family information before you think about having children of your own. In genetics, we can see people of any age, children or adults, whenever they feel ready for an appointment.