

## Your referral

Your doctor referred you to the Adult Genetics Unit. Some possible reasons for referral are:

- > you have health issues which may be due to a genetic condition
- > there is a genetic condition in the family, and you want to know the chance that you and/or your children might get the condition
- > you have a genetic condition and want specialist advice about the genetic aspects
- > you have a family history of cancer
- > you have an increased chance of developing cancer and what to talk about ways to manage this chance

## What is genetic counselling?

Genetic counselling is about:

- > helping people understand genetic information
- > helping people talk to their family about genetic information
- > helping people cope with the effects a genetic condition may have on their own life or their family members' lives
- > helping people make decisions about their health care
- > helping people make decisions about future children
- > helping people make decisions about genetic testing

## Before your appointment

Before your appointment, we may send you:

- > a personal health information sheet
- > a family history form
- > a consent form to allow us to access your medical records
- > a pre-paid return envelope

Please return the forms as soon as possible. The forms are more helpful if you return them before your appointment. This information helps us maximise the usefulness of your appointment.

## Your appointment

You can bring other members of your family or a friend to the appointment.

Most appointments are with a Genetic Counsellor, or a Clinical Geneticist, (a genetics doctor).

Some appointments are in a specialty clinic with a doctor who has genetic expertise in their specialty (e.g. Cardiologist, Endocrinology).

You are encouraged to ask questions and to make your own decisions.

You are supported so you can make decisions that are right for you and your family.

## At your appointment

What happens at the appointment depends on the reason you are referred, but may include:

- > discussing the family history you gave us
- > discussing the problem or condition that has brought you to the clinic
- > a medical examination
- > if a genetic condition is diagnosed, talking about the condition and what it means for you, your children and your close relatives
- > if a genetic test is available:
- > explaining the reasons for a genetic test and the possible test outcomes
- > exploring the possible medical, social and emotional consequences of a genetic test
- > discussing the insurance and employment issues raised by genetic testing
- > if appropriate, and if you agree, arranging for genetic testing to be done
- > if a genetic error is identified we will talk about who else in the family may benefit from testing

## After your appointment

A plan may be made for further information gathering, special tests, or another appointment.

You and your doctor are sent a letter going over what was discussed in the appointment.

Your referring doctor remains responsible for your health care.

## Genetic tests

A genetic test usually involves collecting a sample of blood. Genetic material (DNA) is extracted from the blood sample for testing.

If you have a genetic test, the results will be sent to you and your referring doctor.

If the lab finds a genetic error in your DNA sample we may arrange another appointment to talk about the result.

At a result appointment a clinical geneticist and/or a genetic counsellor will talk about what the result means for you and other members of your family.

If you would like to know more about genetic testing we can give you a detailed leaflet.

## Other places to get information

**Centre for Genetics Education (NSW)**

[www.genetics.com.au](http://www.genetics.com.au)

**Help Me Understand Genetics**

<https://ghr.nlm.nih.gov/primer>

**Cancer Council SA**

[www.cancersa.org.au](http://www.cancersa.org.au)

**Cancer Help Line**

phone 13 11 20

## For more information

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# The Adult Genetics Unit



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