

Genetic counselling is provided by a team of health professionals who work together to provide an individual or family with current information and support regarding problems in growth, development and health that may have a genetic basis.

In summary

- **Genetic counselling aims to provide current information and support to individuals or families about genetic conditions**
- **Genetic counselling is provided by a team of health professionals**
- **Genetic counsellors will work with you to understand the impact of genetic information on you and your family.**

WHAT IS THE ROLE OF A GENETIC COUNSELLOR?

Genetic counsellors provide the most up to date information and support to individuals and families who have a condition that may have a genetic basis.

Where there is a genetic condition in a family, the genetic counselling team may:

- Estimate the chance that other relatives, or children, will be affected by the condition
- Discuss the impact and possible effects on the individual and their family
- For some conditions, develop management strategies
- Refer to appropriate community resources and support groups
- Discuss and arrange appropriate genetic or genomic testing where available
- Discuss, if relevant, prenatal testing and other reproductive options.

A genetic counsellor can provide both verbal and written information about the condition and its impact to assist people in dealing with some of the issues that may arise from the diagnosis of a genetic condition.

Genetic counselling is not primarily *counselling* in the psychological sense, although the genetic counsellor will address emotional and psychological issues raised during a consultation, and may be able to assist individuals in adapting to new information.

WHO PROVIDES GENETIC COUNSELLING?

Genetic counselling is provided by a team of health professionals that may include:

- **Genetic counsellors** who are graduate health professionals with specialist training overseen by the Human Genetics Society of Australasia (HGSA).

Genetic counsellors may work in designated genetics services in major public hospitals or in community settings in non-metropolitan or rural areas with links to the major services.

Increasingly, genetic counsellors are working in the private sector or in public hospitals and specialising in a variety of areas such as reproductive, cancer, and cardiac genetics.
- **Clinical geneticists and other medical practitioners** with expertise in the genetics of their field of medicine e.g. oncologists (cancer genetics) and neurologists (e.g. Huntington disease and Alzheimer disease).
- **Social workers** with a special interest in genetics and particular genetic conditions, work closely with clinical geneticists, genetic counsellors and support groups.

WHY MIGHT I NEED GENETIC COUNSELLING?

Your GP or another healthcare professional may refer you to see a genetics professional:

- When there is a condition that runs in your family and you are concerned that you or your children will develop the condition
- Where a child is affected by an ongoing difference in growth, development or health problems
- Where one or more family members have unusual features, or a serious health problem
- When a couple are blood (genetic) relatives
- Where a pregnancy (or previous pregnancies) has been identified as potentially having a problem
- When there is concern about exposure to some environmental agent such as drugs, medications, chemicals or radiation that might cause congenital conditions
- When you are planning or in the early stage of pregnancy and wish to find out about reproductive carrier screening (referral to private genetic counselling service or discuss with obstetrician).

HOW CAN GENETIC COUNSELLING BE ACCESSED?

The availability of genetics services will vary throughout Australian States and Territories. It is preferable that referral to genetic counselling services is sought through a general practitioner, a medical specialist or other health care professional.

Contact details for genetic counselling services in Australia can be found at www.genetics.edu.au/genetic-services

What happens after referral to the specialist genetic services?

After referral to a genetics clinic it is likely that you will be contacted to collect further information, particularly about your family health history. The information may be collected using a questionnaire or a telephone call. For most patients, an appointment is then offered.

What happens at a genetic clinic?

This will depend on why you've been referred to genetics. Your appointment may include:

- Drawing up a family tree to understand the health problems in your family
- Learning about the genetic condition in your family, it's inheritance and which family members may be affected
- An assessment of the chance of you and your partner passing a genetic condition on to your child
- Support and advice if you have a child with a genetic condition and you want to have another child
- Discussion about genetic and genomic tests, which can be arranged if appropriate
- Help in understanding the results of genetic and genomic tests and what they mean
- Information about relevant patient support groups.

A letter summarising the consultation(s) is also usually provided.

How can I prepare for my appointment to the genetic counselling service?

Before attending a genetic counselling session, it may be helpful to find out as much information as you can about the medical history of both sides of your family as this is the type of information discussed at your appointment. This might include:

- How you are related to each family member, including whether family members are adopted or half relatives
- Any major health conditions that affect family members
- The age of onset of each condition
- Information on miscarriages
- The cause and age of death of family members
- Information on genetic or genomic tests already performed in the family.

It's a good idea to write down any questions you think of before going to a session to make sure they are answered.