Fact sheet **06**

GENETIC COUNSELLING

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

IN SUMMARY

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

WHAT IS THE ROLE OF THE GENETIC COUNSELLING TEAM?

Health professionals providing genetic counselling give the most up-to-date information and support to people and their families who have a health condition that may have a genetic basis.

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

- Advise regarding the chance that other relatives or children will have or develop the health condition
- Talk about the possible impact on a person and their family
- For some health conditions, make health management plans
- Suggest and refer to community resources and support groups
- Talk about and arrange the right genetic or genomic testing if available
- Guide planning a family and offer options for testing in the setting of a pregnancy.

A genetics health professional can talk about and provide written information about the genetic health condition to help people deal with some of the issues that can happen as a result of the diagnosis.

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.

  Genetic counsellors may work in major public hospitals, in private or community health settings, in non-metropolitan or metropolitan services.

  Genetic counsellors sometimes specialise in areas such as reproductive health, cancer, cardiac and neurological genetics
- Although the genetic counsellor may provide support about emotional and psychological issues that come up during an appointment, this is not the same as *counselling* that focuses mainly on mental health support
- **Clinical geneticists** are doctors with extra specialist training in diagnosing and managing genetic conditions. Clinical geneticists may also specialise in a particular area such as the genetics of heart disease or the genetics of learning disability. Other doctors with expertise in the genetics of their field of medicine e.g. oncologists (cancer genetics) and neurologists (e.g. Huntington disease and Alzheimer disease) may also provide a specialist assessment
- **Social workers, psychologists and counsellors** with a special interest in genetics and particular genetic conditions, may work closely with clinical geneticists, genetic counsellors and support groups.

Content updated November 2021
NOV21/V1 NS12671
SHPN: (HETI) 240967

WHY MIGHT I NEED GENETIC COUNSELLING?

Reasons your family doctor or health care professional may refer you to see a genetics professional:

- When there is a condition that is in the family and you are worried that it may develop in you, your children, other family members or in pregnancy
- Where there may be an ongoing difference in growth, development or health in a person or in pregnancy
- Where one or more family members have features or a health concern that might be linked to a genetic condition
- When a couple are blood (genetic) relatives
- When there is concern about exposure to some environmental agent such as drugs, medications, chemicals or radiation that might cause health or developmental conditions
- If found to have a higher chance of being a genetic carrier of a health condition. This may be important to think about when planning a family or early in a pregnancy (reproductive genetic carrier screening).

HOW CAN GENETIC COUNSELLING BE ACCESSED?

The availability of genetics services will vary throughout Australian States and Territories. It is preferred that you get a referral to genetic counselling services from a family doctor, a medical specialist or other health care professional.

What happens after referral to a genetics service?

After referral to a genetics clinic you will often be contacted to collect more information, such as your family health history. A telephone or video call may be made before an appointment. In some instances health information may be collected using a questionnaire.

What happens at a genetics clinic?

This will depend on why you have been referred. Your appointment may include:

- Drawing a family tree to understand the health problems in your family
- Clinical examination by the genetics team to help make a diagnosis of a genetic condition. If you are comfortable with this, photos may be taken and stored securely to help the team remember and document the details
- Talking about how a genetic condition may be managed or treated in members of the family who may have the condition, or who have a higher chance of developing this
- Learning about a genetic condition in your family, and the way it may be inherited
- Talking about the chance that you and your partner may pass 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
- Talking about options for the right genetic tests and arranging these tests. This may typically involve a collection of blood or a saliva sample if you want the test
- Help with understanding the results of genetic tests and what they mean for you and your family
- Information about patient support groups.

A letter summarising the appointment(s) may also be provided.

How can I prepare for my appointment with the genetics service?

Before coming to an appointment, it is 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 talked about at your appointment. This might include:

- How you are related to each family member, including whether family members are adopted or half-relatives
- Any health conditions that affect family members

- The age that symptoms or signs of the condition start in a family member
- Information on miscarriages
- The cause and age of death of family members
- Information on genetic or genomic tests already done in the family.

It is also worth bringing any questions you might have to an appointment to make sure they are answered.