

Important points

- Genetic counselling provides
 - Information about the condition running in the family and its impact
 - Supportive counselling regarding the diagnosis and risk for a genetic condition in the family
 - Diagnostic, carrier, predictive and presymptomatic genetic testing where appropriate
 - Management strategies where appropriate
 - Referral to appropriate community resources, including support groups.
- The health professional team providing genetic counselling may consist of clinical geneticists or other medical specialists, genetic counsellors and social workers
- Genetic counselling is provided as part of a comprehensive genetics service whose elements include clinical, laboratory and education
- The availability of genetic counselling services varies throughout Australia and New Zealand
 - Contact details available at <http://www.genetics.edu.au/Genetics-Services/genetic-counselling-services>

Genetic counselling is provided by a team of health professionals who work together to provide an individual or family with current information and supportive counselling regarding problems in growth, development and health that may have a genetic basis. This can assist families and individuals to understand and adjust to the diagnosis of a genetic condition, its implications, and make informed decisions. Genetic testing may be offered where appropriate.

What happens in genetic counselling?

The consultation

During the consultation:

- A family health history is collected to provide information about the health of family members
- A diagnosis of a genetic condition may be made or confirmed in a pregnancy, after birth, in childhood or later in life. The diagnosis may be made on the basis of clinical features, biochemical tests or genetic tests (see Genetics Fact Sheet 21)

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

- Estimate the risks that other blood relatives, or future children, will be affected by the condition. Often, however, a person is reassured following genetic counselling to find out that a condition is unlikely to recur in themselves or their family
- Discuss the impact and possible effects on the individual and their family in a supportive atmosphere
- For some conditions, develop management strategies
- Refer to appropriate community resources, including support groups for the condition where available or to a general genetic support group
- Discuss and arrange appropriate genetic testing, including diagnostic, carrier, predictive and presymptomatic testing, where available (see Genetics Fact Sheet 21)

- Discuss, if appropriate, prenatal testing and other reproductive options to ensure that any decision is made on an informed basis. Many genetic conditions can be diagnosed before birth (see Genetics Fact Sheets 17 & 18)
 - If a genetic condition is identified by prenatal diagnosis, genetic counselling is the means by which current information and support is provided so that an informed decision can be made regarding the continuation of the pregnancy
 - Where there has been exposure to a potential *teratogen* (chemical, drugs, medications, radiation or other environmental agents which can cause congenital conditions), genetic counselling provides an opportunity to obtain current information and support and discuss strategies and options

Both verbal and written information about the condition and its impact is provided to assist people in dealing with some of the issues that may arise from the diagnosis of a genetic condition

Follow up

After the initial consultation an opportunity may be provided to go over the information and offer on-going support as families and individuals learn about the condition. It is very common for people to think of many questions after the genetic counselling session, and new questions also arise as a condition develops.

These opportunities may be provided in further consultations, if geographically possible, or by telephone.

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

Who provides genetic counselling?

Genetic counselling is provided by a multi-disciplinary team of professionals that may include:

- **Clinical geneticists and other medical practitioners** with expertise in the genetics of their field of medicine eg oncologists (cancer genetics) and neurologists (eg Huntington disease and Alzheimer disease)

- **Genetic counsellors** who are graduate health professionals with specialist training and certified by the Human Genetics Society of Australasia (HGSA) to provide genetic counselling. A certified genetic counsellor is a fellow of the HGSA (FHGSA genetic counselling). Associate genetic counsellors are graduate health professionals in the process of completing the requirements of the HGSA to become a certified genetic counsellor. Genetic counsellors may work in designated genetic counselling 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 specialising in areas such as reproductive, cancer and neurological genetics.
- **Social workers** with a special interest in genetics and particular genetic conditions, work closely with clinical geneticists, genetic counsellors and support groups

When should genetic counselling be sought?

Situations indicating referral for genetic counselling may include:

- When there is a condition that runs in a family and individuals are concerned that they or their children will develop the condition
- Where a previous child is affected by a serious problem in growth, development or health

- Where one or more family members (blood relatives not related by marriage) have unusual features, or a serious health problem
- When a couple are blood (genetic) relatives (see Genetics Fact Sheet 16)
- Where a pregnancy has been identified at increased risk for a fetal abnormality
- When there is concern about exposure to some environmental agent such as drugs, medications, chemicals or radiation that might cause congenital conditions

How can genetic counselling be accessed?

The availability of genetics services will vary throughout Australian States and Territories and New Zealand. Sometimes the service is based in specialist paediatric, oncology, neurology or obstetric departments of a hospital.

It is preferable that referral to these genetic counselling services is through a general practitioner, a medical specialist or other health care professional.

Contact details for genetic counselling services in Australia can be found at <http://www.genetics.edu.au/Genetics-Services/genetic-counselling-services>

Other Genetics Fact Sheets referred to in this Fact Sheet: 16, 17, 18, 21

Information in this Fact Sheet is sourced from:

Harper P. (2010). *Practical Genetic Counseling (7th Edition)*. London: Arnold

The Human Genetics Society of Australasia (2008) Process of Genetic Counselling. Policy No: 2008GL01 Available from <http://www.hgsa.org.au> [Accessed March 2012]

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