

How might my family respond to the information?

Some people may not be prepared to hear the information and therefore might be surprised, shocked or even angry that you have brought it to their attention.

All of these responses are normal. Try to remain calm and remind them that both you and the genetic clinic felt that it was important to share this information with them. Remind them that they can take their time to absorb the information and talk to you later. They can also contact the genetic clinic or their GP directly for more information about the genetic diagnosis.

If a family member says they do not want to know any more information, it is important to respect their right “not to know”. As long as they are aware of where they can go if they change their mind and do want more information at a later time, you have done your best.

Stay in touch

Some genetic conditions are still being researched and as new treatments and options become available, the genetic clinic will be the best place to discuss these. It is important that you update the genetic clinic if you move or your contact details change.

More Information

To find your local genetic clinic or learn more about genetics contact:

The Centre for Genetics Education

Telephone: 9462 9599

Email: contact@genetics.edu.au

Web: www.genetics.edu.au

For information about patient privacy see:

health.nsw.gov.au/patients/privacy/

and

health.nsw.gov.au/patients/privacy/Documents/privacy-leaflet-for-patients.pdf

Talking to your family about a genetic diagnosis or test result

Some tips that may help



Centre for
Genetics Education

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Your genetic information (obtained by a test result or a diagnosis) is personal but can have implications for other members of your family.

This brochure provides some tips and ideas for how to discuss this together.

Why would I share genetic information with my wider family?

When a genetic condition is diagnosed in an individual, often it can mean that other family members will also develop or have an increased risk of developing the same condition.

Informing other family members about a genetic condition may help them to be prepared or screened for symptoms before they become severe. Sometimes this can even save their lives. In other situations, family members may benefit from having this information in pregnancy or when they are planning to have children.

How can I prepare myself for the discussion?

First and most important is to have the correct information. If you or a close family member is given a genetic diagnosis, be sure to have it documented by a genetic specialist.

Most genetic clinics will provide families with a detailed letter summarising the genetic diagnosis and any genetic test results.

The genetic clinic can also help you identify who in the family may benefit from knowing about the genetic information.

If the diagnosis is in a family member other than yourself (e.g. your child or partner), it is important to discuss with them the fact that you would like to inform other family members about the diagnosis. Some people need time to adjust to a new diagnosis and giving them time to do so before involving other family members can be helpful.

However, the sooner other family members are informed, the sooner they can find out about how the information may affect them. They may also become a source of support for you or other family members who are facing the same issues.

What can I do to help keep the message clear?

Families communicate in different ways. Some live close by and see each other regularly while others can be scattered in different cities or even countries around the world. For some members in the family, a telephone call or visit may be the best way to discuss and share genetic information. For others, it may be through a letter or email. There is no “one size fits all” solution and so it is best to think about what works for each family member with whom you would like to share information with.

Here are some tips that may help:

- Ask your genetic clinic for a summary of the information that is important to share with family members. They may also be able to provide you with some written information (letters or brochures) that you can pass on to family members.
- If possible, start with a close family member with whom you have a good relationship. They can then help you to contact other family members with whom you may not be as close.
- Take it slowly, and with the help of those you do contact, you may be able to share the information with as many family members as possible for whom the information may have implications.
- Remember that even within the same family, there will be different personalities, cultural beliefs and therefore different responses to the same information.

