

FACT SHEET

COMMUNICATING WITH FAMILY ABOUT GENETIC RISK

Sharing information with our family members happens all the time and we often don't think at length about how we do this. However, often when families are asked to share genetic risk information, they can express that the tasks feel overwhelming and daunting.

Research of family members in whom receive information about genetic risk information from other family members are generally positive and family members value the opportunity to be informed about potential health risks and the ability to act on them.

With some forward planning and willingness to be flexible in your approach, it is possible to communicate genetic risk information in a supportive and respectful way.

First steps

When you are considering sharing genetic risk information you may wish to ask yourself the following questions;

- Are you/your family member ready to disclose/hear genetic risk information?
- What do you want to share?
- How do you want to share information?
- Are you prepared to be contacted again?

Are you ready to disclose?

It may be helpful to ask yourself how you feel about the task involved to help identify if there are any aspects that concern you. This will help you identify if there is anything you seek help about or may like to consider further. Addressing your concerns may help you feel more at ease when you do connect with your family member.

Common concerns are;

- My family member may have no context to the information, e.g. they are not aware of the family history
- I am not sure it is my place to tell them this information
- I don't want to be the 'bearer of bad news'
- I am worried my family member won't listen to me
- I'm unsure how my family member will respond
- I'm unsure how my family member will access the care they need.

When to share information?

You may wish to think further about the age of the family member, location, your relationship with and to the family member. Putting yourself in their shoes and considering how your family member best like to hear this information can be useful. There are additional fact sheets for communicating with children, young people and family members in whom you may have limited contact that you may find helpful if applicable.

What information to share?

It is often difficult to know how much detail to go into. The main pieces of information to share are;

- what could the information mean to my family member and their family,
- what are their options,
- how can they access more information and/or support.

Think about sharing general concepts first and then become more detailed if your family members wish you can be a good place to start.

Genetics clinics can often provide a letter that summarises the main points that you can share with your family members. Genetics services may be able to locate a genetics services that is more local to your family member so they know who to contact for more information.



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How to share information?

You may wish to consider

- Whether you wish to do this in person, email, phone or letter.
- Give your family member warning that you want to talk to them about something important so they can prepare and elect to bring a support person
- Ensure you are in a location that is suitable to share information e.g. a space or time where they you or they can be in a quiet space, concentrate on what you are sharing with them and away from people that they may not want to hear that information
- Leave them with written information, so they can revisit the main points you discussed and include details of how they can get more information.

Conversations about genetic risk often happen over time. Be explicit about whether you are willing to be contacted again and how they can do so. If you are not willing to be contacted, suggest they speak with their doctor or a local genetics clinic.

Points to remember

Take it slow

Focus on the positives and value of the information

Not all family members will want to act on the information you share– this is okay and it is best to be respectful of their decision, even if you don't understand it

Recruit the help of others if you feel you need it

Take care of yourself, sharing information can be hard when you are also managing your own health. Make sure you balance the task of sharing information with positive and enjoyable things as well.

Need help?

It is not uncommon to require assistance in sharing information with family members. This help may come from genetics clinics, health professionals, family or friends. If there are aspects of sharing information with your family members that you are unsure about reach out and get the help you need.

