

FACT SHEET

COMMUNICATING WITH FAMILY OF LIMITED CONTACT ABOUT GENETIC RISK

Informing family members in whom you have limited contact can pose additional challenges.

What might be the reasons for a lack of contact? Sometimes it is just a physical distance. However, despite the improvements in technologies such as video calls, email and social networking, when distance is involved communicating health related information can still feel challenging.

Other times it can be because of relationship breakdowns or due to life getting busy and contact becoming more infrequent.

Whilst the principals of communicating information with family members remain the same, (see fact sheet on general communication) being either geographically distant and/or not having a close relationship can make it more difficult to know how best to approach the situation and how your relative might respond. This can cause some people to be hesitant in disclosing and in some cases not disclosing at all.

However, with some forward planning and willingness to be flexible in your approach communicating genetic risk information is possible and can be done in a supportive and respectful way. Similar to communicating information to close family members the main principles apply being;

- Are you/your relative 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?

When you are geographically distant or where you don't have a close relationship it is natural to have concerns about the process of communicating genetic risk information.

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 need to work through or consider further and will help you feel more at ease when you do connect with your relative.

Common concerns are;

- My relative 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'
- My relative won't listen to me
- I'm unsure how they will respond
- I'm unsure how they will access the care they need.

What information to share?

It is important to remember the main pieces of information are;

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

Genetics clinics can provide a letter that summarises these points that you can share with your family members. These can be translated into different languages if needed. Genetics services may be able to locate a genetics services that is more local to your relative so they know where to contact for more information. If your relative lives in a country with little access to genetics services, information about relevant risk management strategies may be included and your family member can take this to their local doctor to discuss their options.



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How to share information?

There are a variety of ways to do this but it can be helpful to consider if you want to do any preliminary work such as find out how your relative is and if they are ready to receive the information you are wanting to share. This could be done via making social contact with your relative prior to disclosure and/or enquiring through other family members. Starting small and telling your relative you have important health information to share with them first and enquiring how and when they would like to discuss this may give your family member a sense of control over the discussion and how it happens e.g. video call, email etc.

Being clear about why you feel it is important but be mindful of being respectful of your relative's wishes as they may view the information differently and make different choices to you. This can be helpful particularly where family members may hold different values and beliefs from yours. Statements such as "I am contacting you as I felt you had a right to decide whether you wish to hear this information?" can be a good way to start.

In some cases, it may not be possible to personally deliver or share information. Or you may wish to remain anonymous. If you opt to send a letter or information anonymously it can be helpful to include a note that acknowledges that the letter may be unexpected and explains your reasons for sharing the information.

Are you willing to be contacted again?

Be prepared that sharing information often happens over time and may require more than one conversation. Starting slowly and sharing information in small pieces can help family members more readily understand its importance. It can be helpful to your relative if you are explicit about whether you are willing to be contacted again and how they can reach you. If you are not willing to be contacted you may wish to suggest they contact a local doctor or genetics clinic.

Involving someone else?

In some situations, it may be helpful to consider whether there is someone else who may be able to assist you in communicating with the family member involved. Questions to ask yourself include; Is there someone who has a closer relationship or lives closer to them?

When communicating with more extended family members it can be helpful to think about your relationship with the person who you wish to share the information with and what are the usual ways your family communicates important information to family members of this relationship. E.g. if it is your cousin, can you tell your aunt/uncle and they can tell your cousin. Thinking about the usual patterns of communication may help you identify if there is someone you may be able to ask to help you.

