Communicating with family about genetic cancer risk

Inherited cancers are different from other cancers because the risk can be passed through generations of the family, making it important to talk to your family about the potential risks. This conversation can be difficult and uncomfortable, especially when discussing sensitive topics like cancer. However, it's essential, as one in seven women in Australia will face breast cancer in their lifetime.

If a genetic mutation is found in one family member, it is important to inform other family members so they can consider their options, including having genetic testing themselves. A genetic counsellor can support you, identifying people in your family for whom this information is important and can be offered genetic testing. Family members can also visit their GP to learn more about the genetic information.

Although sharing genetic cancer risk information can feel overwhelming, research shows that family members generally appreciate being informed about potential health risks and the opportunity to take action. With some planning and a flexible approach, you can communicate this important 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 about sharing this information with your family. 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.

- *What is the benefit of my family knowing about their risk of an inherited cancer condition?*

Knowing that they are at risk can allow them to organise genetic counselling and, if needed, genetic testing, screening and medical care aimed at preventing cancer. This can give them more control over their health and help them live a longer, healthier life.

- I feel bad about telling my family they might be at risk of hereditary cancer. What can help make it easier?

People often feel quite unsure about what to say to their family. Sometimes it helps to talk over what to say with your doctor, genetic counsellor or someone at the Family Cancer Clinic. It can also help to start by telling those people in your family that you feel most comfortable talking to. You may also want to share the letter you have been given, or information available from the Family Cancer Clinic.

- *I come from a big family and I'm not even sure who needs to know?*

Your doctor or genetic counsellor can talk to you about which blood relatives should be alerted about their risk. Once you have a list it will be a matter of working out the best way for each person to be contacted. Think about whom else in the family can help you to do this.

- *I think I will be OK talking to my close relatives, but what about the ones I'm not normally in touch with?*

For a variety of reasons, you may not be in touch with all family members. It can be really difficult to contact family members you haven't seen or heard from for a while. You may be able to ask a family member who is in touch with other parts of the family to pass on the information. Talk to that person first; perhaps give them a copy of the letter from the Family Cancer Clinic or genetic counsellor explaining about genetics, screening, and management. Together you can plan who needs to be told and how they can best be contacted. Some families have a self-appointed family historian with up-to-date family information that can be helpful.

- *What can I do if a family member reacts angrily and makes me feel uncomfortable?*

This can be a difficult thing for you but be reassured that anger can be a normal response in such circumstances and is not necessarily directed at you personally. Stay calm and don't respond angrily or defensively. Tell them you felt they had a right to know information that might affect their health, or their family's health in the future. Emphasise that nothing is being forced onto them and they might like to think it over or discuss it with others. Leave the lines of communication open so they know they can get back to you without losing face if they change their mind.

- *What if a family member says they "don't want to know"?*

Respect their right "not to know". People have equal rights "to know" and "not to know" and it's their choice. Reassure them that they have been notified out of concern for their wellbeing and that of their children. Emphasise that if they change their mind or if their children wish "to know" that you will be available to talk again and can give them contact details of someone who can help.

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 wishes 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.

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 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 to Inherited Cancers Australia.

These resources were researched and produced by Garvan Institute of Medical Research, who have kindly given ICA permission to repurpose them for our community.

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