

Sharing Your Inherited Cancer Risk with Family



Why talk to your family about inherited cancer risk?

Inherited cancers are unique from other cancers because the risk can be passed on to children. Sharing cancer risk with children at any age can be difficult and complicated. Issues include the best age to share information, how to share information with children, and what information is appropriate to share. Having a conversation about cancer and the medical history of your family is probably up there as one of the most uncomfortable and upsetting discussions you can ever have. But it's a must, as the statistics show. Around one in seven women in Australia have a lifetime risk of breast cancer. If there is a history of breast cancer in your family, you could be at an increased risk, and having the conversation with your family may help save lives.

If a genetic mutation is identified in one person, it is important that the relevant family members should be notified and offered testing, known as predictive genetic testing. Working with a genetic counsellor, you will work back through three generations of your family to identify high-risk family members who are most likely to benefit from genetic testing. It's best to also have this conversation as a family, or to encourage family members to visit their GP, so that all family members can contribute and even fill in the medical gaps of generational history.

How do I talk to my family about genetic cancer risk?

For some people, contacting family members is straightforward. They are thankful for information about the family's health because it allows them to make informed choices. However, sometimes it may not be straightforward, or questions may arise. Consider the questions below to help you plan to inform your family members:

1. What is the benefit of my family knowing about their chance 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.



2. I feel bad about telling my family they might be at risk of inherited 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.

3. 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.

4. 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, we may not be in touch with all family members. It can be really hard to get in touch with those we haven't seen or heard from for a while to give them information about a health problem. 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.

5. 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.

6. 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 well-being and that of their children. Emphasise that if they change their mind or if their children wish "to know", you will be available to talk again and can give them contact details of someone who can help.