

# Informing family members about hereditary cancer



Family members will generally be very thankful to receive information about hereditary cancer, as it allows them to make informed choices. However, questions may arise, so it is helpful to be prepared ahead of time.

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

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

## **I come from a big family, so who actually needs to know?**

Your doctor, genetic counsellor or staff from the Hereditary Cancer Registry 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 who else in the family can help you to do this.

## **I feel bad telling my family they might be at risk of hereditary cancer. Is there anything that would help make this easier?**

People often feel quite unsure about what to say to their family. It may help to discuss your approach beforehand with your doctor, genetic counsellor or someone at the Hereditary Cancer Registry.

Also, begin by talking to those family members you are closest to and feel most comfortable with. It may be helpful to share the letter you have been sent regarding the condition, and further information is available from the Hereditary Cancer Registry.

## **Talking to my close relatives should be fine 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 of your family members. Consequently, it can be difficult to contact those you 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 others in the family to pass on the information. Talk to that person first, and perhaps give them a copy of a brochure from the Hereditary Cancer Registry and/or the letter from your clinic or doctor, explaining about genetics, screening and management.

Together, you can make a plan about 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 situation; however, be reassured that anger can be a normal response in such circumstances and is not necessarily directed at you personally.

Stay calm and try not to 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 own 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.

## Key services

### Hereditary Cancer Registry

Each state in Australia has a register for families living with hereditary cancer conditions. Registers may provide family members with up-to-date information, a screening reminder service, contact with other families and regular newsletters. The services provided, and the range of hereditary cancer conditions covered, differ from state to state. Please check with your local state register to find out more.

#### NSW & ACT Hereditary Cancer Registry

**Phone:** 1800 505 644 (toll free)

**Website:** [cancer.nsw.gov.au/hereditary-cancer-registry](http://cancer.nsw.gov.au/hereditary-cancer-registry)

The NSW & ACT register covers a range of hereditary bowel cancer syndromes – please see the website for more information.

### Your local family cancer service

Each state in Australia has a number of family cancer services. Genetic counselling and information regarding genetic testing can be obtained from these services. A list of contact details for family cancer clinics throughout NSW and the ACT is available from the NSW & ACT Hereditary Cancer Registry. Information about cancer genetic services in NSW can also be found at [www.canrefer.org.au](http://www.canrefer.org.au)

### Cancer Council 13 11 20

Cancer Council 13 11 20 is a telephone information service provided by Cancer Council NSW for people affected by cancer. For the cost of a local call, you can talk about your concerns and needs confidentially with oncology health professionals.

Helpline consultants can also put you in touch with appropriate services in your area.