

CONTACTING FAMILY MEMBERS ABOUT HEREDITARY CANCER

When questions arise ...

Most of the time contacting family members is fairly simple. They are thankful for information about the family's health because it allows them to make informed choices. However, sometimes questions may arise and it helps to think about them ahead of time so you are prepared.

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.

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 Hereditary Cancer Registry. 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 Hereditary Cancer Registry.

I come from a big family and I'm not even sure who 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 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 a brochure from the Hereditary Cancer Registry and/or the letter from the 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 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.

NSW & ACT Hereditary Cancer Registry

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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" 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. The register can provide family members with up-to-date information, a screening reminder service, contact with other families and regular newsletters.

You can call the NSW & ACT Hereditary Cancer Registry toll free on 1800 505 644, or visit our website: http://www.cancerinstitute.org.au/cancer_inst/programs/hcr.html

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.

THE CANCER COUNCIL HELPLINE

Cancer Council Helpline 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. You can call the Cancer Council Helpline on 13 11 20.