

Telling your family that you are planning to have genetic testing



If you have been identified as having a strong family history of cancer, you may be thinking about having genetic testing, to see if you are at high risk of cancer.

This information sheet aims to guide you through considerations for sharing your plans for genetic testing with other members of your family.

Although a genetic test can provide information for you, it can also have implications for your family.

How is my genetic test relevant to anyone else?

Your decision about **genetic testing** for cancer risk may affect your family. You may find that you have a gene change that puts you and your family at higher risk of a cancer. **Gene changes** can be passed down for many generations in families. So, if you find that you have a gene change, other blood relatives will wonder if they, too, have inherited the change.

The decision to talk to your relatives about new genetic information is not always straightforward, and can be a daunting task. The staff members at your **Family Cancer Centre** are experts at helping people pass on genetic information to their families, and they will be happy to help you with this.

Once genetic information and testing is available in a family, relationships in the family can change. The best way to prepare yourself for such changes is to think about and discuss the possible outcomes of genetic testing with your close family members before you embark on the genetic testing process.

How would my test results benefit other family members?

If family members are informed that they may have inherited an increased risk of cancer, they may:

- choose to contact a Family Cancer Centre to get more information about genetic testing
- choose not to seek genetic testing themselves, but increase their health awareness and/or **screening**
- choose not to take any action.

By passing on information about genetic risk to your family members, you allow them to make a choice.

Who would I tell?

Genetic information is most relevant to:

- blood relatives – not people related by marriage or adoption
- adults – you can discuss your own testing with children, but generally genetic testing for cancer risk is not offered until people are legally adults. There are exceptions to this, so please ask your genetic specialist if you are not sure.

How would I tell them?

There may be some family members who you feel comfortable enough with to talk to directly about an inherited cancer risk. You may decide to see them face-to-face or speak with them over the phone.

With others, you could use a letter in your own words, or the Family Cancer Centre will provide you with a letter.

Sometimes it's hard to contact relatives you don't know well or haven't had contact with for years. Possible approaches are:

- Talk to family members you have easy contact with, and ask for their help in passing on information to more distant family members. You may find that one person in each branch of the family can contact everyone in that branch.
- Ask the Family Cancer Centre for a letter that you can give/send to family members you would not feel comfortable talking to. You can also give this letter to closer family members to pass on to other, more distant relatives.
- Some families have used family gatherings to discuss genetic information and risk. However, this method does not work for all families, so carefully consider the effect this might have on you and other family members.

How are people likely to react?

People can react in many different ways to the news of a gene change in the family.

Many family members respond well to being told of a possible risk. They see this as allowing them to make decisions about their and their family's health.

However, sometimes people don't want to know about a possible genetic risk in the family. For you, this may be difficult to understand: you may feel that you are informing them for the good of their own health. However, it is important to understand and respect each person's choice on whether to follow up on the information you give them.

Although you may feel differently, you are not responsible for other family members having genetic testing or screening. You just need to pass on the information that you have.

How can a Family Cancer Centre help?

Staff at your Family Cancer Centre have experience in helping families discuss complex genetic information. They are available to help you through this process. They can help by suggesting ways to approach a situation, or they can prepare written information for family members that you or the centre can send to relatives.

Your Family Cancer Centre will be aware of similar centres in other cities, towns, states and countries. So if you have family members in other places, your Family Cancer Centre can assist in finding local support for them.

What that word means

Family Cancer Centres Centres where people can get information about a family cancer history. Their services include genetic counselling, testing, medical advice, psychological support and information about research.

family history A careful assessment by a Family Cancer Centre of cancer occurrences in a family.

gene change A change somewhere in a gene. A change may be inherited or be caused by an error while a cell is reproducing itself, by factors such as some chemicals or viruses, or by events that science is yet to discover. A change in a gene may lead to disease such as cancer. However, people with a change in a gene that may predispose to cancer don't always get cancer. Also known as a gene error or gene mutation.

genetic testing Testing for gene changes which may explain why a disease has occurred or whether a disease is more likely to occur.

screen / screening Testing all people at risk of developing a certain disease, even if they have no symptoms. For example, all women over the age of 50 are encouraged to have regular mammograms, since all women above this age are at increased risk of breast cancer and mammogram is an effective way to find breast cancer early.

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