

Sharing information on genetic cancer risk – communication templates



These are example written and verbal communication templates that you can use as a guide when communicating with your family.

Please alter them to best suit your own communication style and/or relationship of the person you are speaking with.

Example script for sharing genetic risk verbally

Hello

I am getting in touch with you because I have some important information that I feel you have a right to be informed about. This information may be relevant for your health and/or the health of your children.

Before I continue, I am happy for you to take some time to think about if and/where/how you might like to discuss this in further detail. You may also like to have someone else with you during the conversation. (It you may be a good idea to set up a time to discuss further in person or via skype if you are not in the same area).

(Be prepared for the person to wish to discuss this immediately. Alternatively, be prepared for the person to shut down the conversation – don't push if they are not ready)

(If they wish to continue the discussion....)

It has been found that our family has been shown to have a genetic condition caused by a change in the gene known as (insert name of gene). The (name of genetics service) holds information about this family gene change.



Those family members who test positively with this faulty gene have an increased risk in developing (insert cancer types OR certain cancer types). If they have children, they have a 50% risk of passing the gene fault to their child(ren).

Not everyone who inherits the gene change will develop cancer. It is possible to find out if you have or have not inherited the gene change by having an appointment with a genetics service which will organise a genetic test (blood test). If you have inherited the gene change there are effective ways of managing the increased cancer risks.

Not everyone wants to know if they have or have not inherited the gene change although it is still important to get advice from genetic specialists on the type and frequency of medical check-ups which can still be accessed without having to have a gene test.

If you would like to know more about any of this information, it is best to call your local genetics clinic and ask to speak to a genetic counsellor or if you would prefer, I can give you details of the genetics clinic I have been speaking with. Appointments and the genetic tests arranged by a genetics clinic are often free of charge. If you attend for an appointment you are not under any obligation to have a genetic test.

If you do not wish to have a genetic test, I strongly encourage you to have an appointment with a genetic service or local doctor. I have been advised that cancers can be prevented, or detected and treated at an early stage if people follow risk management recommendations, even if they do not have a test.



Example letter template for sharing genetic cancer risk in writing

To (insert name),

I am writing to share with you some information that may be relevant for your health and/or the health of your children. It has been found that our family has been shown to have a genetic condition caused by a change in the gene known as (insert name of gene).

The (name of genetics service) holds information about this family gene change, our family reference number is (insert name).

A woman who has inherited this gene change:

- is at increased risk of developing (insert cancer types OR certain cancer types).*
- has a 50% of passing the gene fault onto their child*

A man who has inherited this gene change:

- has a small increased risk of developing (insert cancer types OR certain cancer types)*
- has a 50% chance of passing the gene fault onto their child*

Not everyone who inherits the gene change will develop cancer.

It is possible to find out if you have or have not inherited the gene change by having an appointment with a genetics service which will organise a genetic test (blood test). If you have inherited the gene change there are effective ways of managing the increased cancer risks.

Not everyone wants to know if they have or have not inherited the gene change although it is still important to get advice from genetic specialists on the type and frequency of medical check-ups which can still be accessed without having to have a gene test.



If you would like to know more about any of the information contained in this letter, please call your local genetics clinic and ask to speak to a genetic counsellor. Details of a genetics clinic can be found at (insert details) or arrange to see your local doctor who can also help you get more information.

Appointments and the genetic tests arranged by a genetics clinic are often free of charge. If you attend for an appointment you are not under any obligation to have a genetic test.

If you do not wish to have a genetic test, I strongly encourage you to have an appointment with a genetic service or local doctor. I have been advised that cancers can be prevented, or detected and treated at an early stage if people follow risk management recommendations, even if they do not have a test.

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



Garvan Institute
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Visit our website for more information:

inheritedcancers.org.au