inherited CANCERS AUSTRALIA
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Understanding your family history of cancer

What to gather, where to start, and why it can help

Do you know your family history of cancer?
What if parts of the family history are missing, unclear, or difficult to ask about?

Knowing your family history of cancer can help you and the health professionals involved in your care understand whether inherited cancer risk may need a closer look.

You do not need to know everything before taking the next step. Gathering what you can is helpful. So is naming what you do not know, what feels unclear, and what may be hard to find out.

This can help your GP or genetic counsellor understand your situation and what support may help.

Why family health history can matter

Most cancer is not inherited. Sometimes cancer occurs in families by chance, or because family members may share lifestyle or environmental factors. But in some families, **cancer may be linked to an inherited gene change**, also known as a pathogenic variant. This can include gene changes in *BRCA1*, *BRCA2*, *ATM*, *PALB2* and those linked to Lynch syndrome.

Family health history can help your GP or genetic counsellor understand whether there are patterns that need a closer look.

You do not need to interpret these patterns on your own or have all the answers before the appointment. It may simply help to bring what you know, including any details that feel uncertain or incomplete.

Family history details that may be helpful to mention

If you are able to gather some family health history, it may be useful to write down details such as:

- Who in your family has had cancer
- What type of cancer they had, if known
- How old they were when they were diagnosed, if known
- Whether the cancer occurred on your mother's side, father's side, or both sides of the family
- Whether anyone had more than one cancer diagnosis
- Whether anyone had a rare or uncommon cancer, or a cancer presentation that seemed unusual
- Whether there are relatives whose cancer history is unknown, unclear, or difficult to access
- Your ancestry or family background, if you know it and feel comfortable sharing it

These details do not automatically mean there is inherited cancer risk. They are simply useful information to share with a GP or genetic counsellor, who can help you understand whether anything needs a closer look.

For a practical way to write this information down, you may find **ICA's Family Health History Mapping Tool** helpful. You do not need to complete every section before speaking with a genetic counsellor.

When family health history is not straightforward

It is common to have gaps in your family health history. Many people do not know all the details.

You may not know who had cancer, what type of cancer they had, how old they were, or which side of the family the history came from. You may also have limited information because of adoption, family separation, estrangement, migration, loss, or records that are hard to access.

You do not need to solve all of this before speaking with a genetic counsellor.

It can help to bring:

- what you know
- what you are unsure about
- what you cannot find out

These details can help your genetic counsellor understand your family history more clearly. The "Extra support" section at the end of this resource may help you name why family health history can be hard to collect.

When family history questions feel sensitive

Asking about family health history can feel sensitive for many reasons.

In some families, cancer or illness may be private, difficult to talk about, or connected to strong emotions. Family, cultural, faith or community values may also shape how these conversations happen.

You may have questions or concerns about how genetic testing could affect family relationships, responsibilities, children, privacy or future plans.
You do not need to work through these questions on your own before speaking with a genetic counsellor.

It can help to tell your genetic counsellor what feels sensitive or difficult to talk about. This can help them understand your situation and support you in a way that fits your needs.

For more support with this part of the experience, you may find **Genetic testing in the context of family, culture and community** helpful.

What you can do next

You do not need to have the full picture before taking the next step. A conversation with a GP or genetic counsellor does not mean you are committing to genetic testing straight away.

It can simply be a way to understand:

- whether genetic testing may be relevant
- what information may be useful
- what your options are
- what support may help you and your family

You may want to:

- write down what you know using ICA's **Family Health History Mapping Tool**
- note what is missing, uncertain or hard to ask about
- speak with your GP or a genetic counsellor about whether your family history needs a closer look
- contact ICA's **Inherited Cancer Support Service** if you would like help thinking through where to start

Extra support: Why family health history can be hard to collect

This section may help if family health history feels difficult to gather, or if you are looking for words to describe your situation to a genetic counsellor.

What can make it hard	What this may look like	What may help
Cancer or illness is hard to talk about	• Cancer may be spoken about indirectly, kept private, or not named at all. • You may worry about bringing up emotions or creating tension.	• Keep the first step small. You could start with one trusted person, one side of the family, or one question. • You can also write down what people remember, even if the details are not exact.
Details are unclear or incomplete	• You may know that someone was unwell, but not the exact cancer type, age at diagnosis, or which side of the family it came from. • Details may have been passed down in pieces or remembered differently.	• Write down what you know, even if it is not exact. It is okay to note “not sure”, “approximate age”, or “unknown cancer type”.
You are not connected to some relatives	• You may have limited contact with some relatives, be adopted, part of a blended family, or have gaps in information from one side of the family.	• Gather what you can from the people or records you can access. • Tell your genetic counsellor which parts of the family history are missing.
Language or records make things harder	• Medical words may not translate easily. • Records may be overseas, in another language, missing, or hard to access.	• Bring any details you do have. • This might include names, approximate ages, country or place of treatment, or what the family was told at the time.

Helpful reminder: What you know, what you do not know, and what feels hard to find out can all help your GP or genetic counsellor understand your situation and what support you may need.