Information for
patients & families

Hereditary Cancer and Genetic Testing After a Cancer Diagnosis

Procedures, Infusions, Tests

Cancer Care Alberta

Hereditary Cancer Clinic

Your cancer care team offered you a test to check for hereditary cancer. Read more about hereditary cancer and genetic testing in this booklet.

Hereditary Cancer

What is hereditary cancer?

Hereditary cancer runs in families. It can happen when a gene that protects us from cancer has a change that stops it from working. This kind of change is called a pathogenic variant, likely pathogenic variant, harmful variant, or sometimes just a "mutation". A pathogenic variant increases the risk of getting some types of cancer. However, not everyone who has a pathogenic variant in a gene will get cancer.

How do you get hereditary cancer?

A parent has a 1 in 2 (50%) chance of passing a pathogenic variant to their child before birth. If this happens, the child also inherits an increased risk of developing certain hereditary cancers. These cancers, if they happen, usually develop in adulthood.

Is hereditary cancer common?

No, hereditary cancer is not common. About 3 out of 20 (15%) people with cancer have hereditary cancer.

About 3 out of 20 people with cancer have hereditary cancer

When is a cancer hereditary?

A cancer **may be** hereditary if:

- Cancer is diagnosed in someone at a young age.
- The cancer type is rare (for example: "triple negative" breast cancer, breast cancer in someone assigned male at birth, or ovarian cancer).
- Close relatives on one side of a family are diagnosed with the same type of cancer.
- Certain cancer types are all diagnosed in one person, or on one side of a family (for example: breast and ovarian cancer; colon and uterine cancer).

Why does finding out if I have hereditary cancer matter?

Your cancer care team thinks you may have hereditary cancer. Finding a genetic cause of cancer may:

- Help guide your treatment.
- Tell you if you are at increased risk for other cancers.
- Help identify the best cancer screening and prevention options for you and your family.

Do I have to have genetic testing?

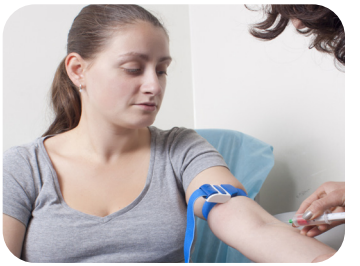
No. Your cancer care team may have offered you genetic testing but **it is your decision whether to have the test**. Your decision will not change your relationship with your cancer care team.

If you still have questions after talking with your cancer care team and reading this booklet, you can:

- Review the online video on cancercarealberta.ca
  Click 'Patients & Families' > 'In Treatment' > 'Procedures, Infusions, Tests'.
- Ask to speak with a genetic counsellor.
- Talk to your regular doctor or a trusted family member or friend about any concerns you have.

Genetic Testing

What is genetic testing?



Genetic testing is usually done with a blood sample. Genes are made of DNA. DNA is removed from the blood and checked for pathogenic variants.

When we do genetic testing for people with cancer we are looking for pathogenic variants related to hereditary cancer. This testing does not check for pathogenic variants related to other health conditions. To learn more about the specific genes included in your test, check with your care team.

Where do I get a genetic test?

You can have this blood test at any Alberta Precision Laboratories (APL) site (including services offered by Dynalife in the past). Take the lab requisition your cancer care team gave you to the lab. You do not need to do anything special to get ready for the test.

Find an Alberta Precision Laboratories site near you:

- Ask your healthcare team.
- Visit albertaprecisionlabs.ca and click on 'Book an Appointment'.

How will I get my test result?

Usually, the person who ordered the genetic test will tell you your test result.

The Hereditary Cancer Clinic Hub will follow-up with you about your genetic test result. You may also be offered an appointment with a genetic counsellor.

Results usually take many months to return. Check with your care team for a timeline.

Private genetic testing is available for a fee. If you decide to get tested privately, make these plans with your cancer care team's help. Not all labs offer the same services. It is important to pick a lab that offers high quality testing, results, and genetic counselling.

What could my test result be?

There are 3 possible test results:

1 No pathogenic variant detected

This is often called a **negative** result and is **the most common result.** It means no variants were found in the genes tested.

If you have a family history of cancer, there is still a chance that your cancer is hereditary. Talk to your care team about your family history of cancer. Further genetic review may be right for you and your family.

About 13 out of 20 people (65%) tested will have a 'negative' result.

2 Pathogenic variant detected

This is often called a **positive** result and it means a pathogenic variant was found in one or more of the genes tested. When a pathogenic variant is found you may be told you have a **hereditary cancer syndrome**.

This result may mean:

- Different cancer treatment is better for you.
- You have a higher risk for another type of cancer and we may suggest changes to your cancer screening.
- Your relatives may have the same pathogenic variant and, if they do, they could be at higher risk of cancer.

About 3 out of 20 people (15%) tested will have a 'positive' result.

3 Variant of uncertain clinical significance (VUS) detected

This is often called an **uncertain** result. A VUS is a genetic variant that is not well understood yet. We don't know if the VUS is a genetic variant that increases your risk of cancer, or just a genetic difference that does not increase your cancer risk.

It is **usually treated as a negative result** (see 'No pathogenic variant detected' above) until more information is found.

About 4 out of 20 people (20%) tested will have a VUS result.

What Are the Benefits and Risks of Genetic Testing?

Genetic testing has benefits and risks. Understanding them will help you decide if the test is right for you.
Check off the benefits and risks most important to you.

Possible Benefits	Possible Risks
☐ Getting a genetic explanation for your cancer.	☐ Getting unclear answers about whether you or your family have a genetic risk for cancer.
☐ Helping identify the best cancer screening and prevention options for you and your family.	☐ Upsetting family members who do not want to know about or discuss a genetic risk for cancer.
☐ Helping confirm what cancer treatments are best for you (like surgery, medication, clinical trials).	☐ Being recommended a cancer treatment medication that is not paid for by Alberta Health Insurance or your health insurance plan.
☐ Learning if you have risks for any other hereditary cancer. This can be a benefit or a risk depending on how you feel about the possibility of getting information like this.	

In 2017, the Genetic Nondiscrimination Act (GNA) became law in Canada. This law protects people from insurance and employment problems based on genetic test results. But, there may be some issues that are not covered by this law.

Some people find making a decision about genetic testing or making sense of a result can be emotionally difficult. Psychosocial Oncology can offer counselling to patients and family members to help reduce emotional distress and explore ways to cope. No referral is needed.

For more information or for contact details, look in the book Newly Diagnosed with Cancer

What Do I Do After I Get My Test Result?

☐ Ask your cancer care team questions, such as:

- Does my result impact my treatment plan? If so, how?
- What are my risks for other cancers and what can I do to help prevent them?
- Does my test result impact my family? If yes, how?

☐ Ask to speak to a genetic counsellor if you have unanswered questions.

☐ Share your results with your regular primary care doctor.

☐ Talk with your family about your test results.

You or your family may find it difficult to talk about the test results.

- Share your results with family in person, by phone, or in a letter.
- Talk to your cancer care team or a genetic counsellor If you need help finding ways to share this information and still protect everyone's privacy.

My notes:

Where Can I Get More Information?

Cancer Care Alberta (ALBERTA) cancercarealberta.ca
- Click 'Patients & Families' > 'In Treatment' > 'Procedures, Lines,Tests'
- Watch the video: **Considering Genetic Testing After a Cancer Diagnosis**

MyHealth.Alberta (ALBERTA)
myhealth.alberta.ca/genetics/understanding-genetics

Hereditary Cancer Clinic Hub (ALBERTA) - 403-943-9979

Canadian Cancer Society (CANADA) bit.ly/ccsgenesandcancer

Hereditary cancer advocacy groups:
- Facing Hereditary Cancer Empowered (FORCE) (USA) facingourrisk.org
- Lynch Syndrome- AliveAndKickn (USA) aliveandkickn.org
- Pancreatic Cancer Canada pancreaticcancercanada.ca
- Prostate Cancer Support Canada prostatecancersupport.ca

Genetic Non-discrimination Act (GNA) information (CANADA)
laws-lois.justice.gc.ca/eng/acts/G-2.5/index.html

Canadian Association of Genetic Counsellors (CAGC) (CANADA) cagc-accg.ca

References:

- GeneReviews® - ncbi.nlm.nih.gov/books/NBK1116/
- Alberta Precision Laboratories NGS gene panel information sheets:
  - Breast/Ovary/Prostate panel information sheet - albertahealthservices.ca/assets/wf/lab/if-lab-hc-gls-br-ov-pr-ngs-info-sheet.pdf
  - Pancreas panel information sheet - albertahealthservices.ca/assets/wf/lab/if-lab-hc-gls-pancreatic-cancer-ngs-panel-info-sheet.pdf
- National Comprehensive Cancer Network (NCCN) (you need to make a free account before you can access the guidelines) - nccn.org/guidelines/category_2

Cancer Care Alberta

Hereditary Cancer Clinic