

# Your Referral to the Hereditary Cancer Clinic — Lynch Syndrome Patient Information Sheet

About 5-10 out of 100 diagnoses of cancers are passed on in families (hereditary). This can happen when there is a change in a gene (mutation).

## Hereditary cancer is suspected when:

- there are unusually young diagnoses of cancer in a family
- many family members from many generations develop the same type of cancer
- families have both of the above

## What is Lynch Syndrome?

A hereditary cancer syndrome is when a person has a greater chance of developing certain cancers because of a gene mutation.

Lynch syndrome increases a person's chance of developing different types of cancer such as uterine (endometrial) and colorectal cancer. Lynch syndrome is linked to mutations in certain genes called MLH1, MSH2, MSH6, and PMS2.

## Why am I being referred to the Hereditary Cancer Clinic?

Since about 3 to 5 out of 100 diagnoses of all endometrial cancer are thought to be related to Lynch syndrome, we try to screen all endometrial cancers in Alberta to assess risk for this syndrome. Your tumour tissue was tested and it suggests you **might** have Lynch syndrome.

The Hereditary Cancer Centre can help you find out if you have Lynch syndrome. They will review your personal and family history and will likely offer you genetic testing.

## Why should I attend a Genetics appointment?

A Genetics appointment will help you:

- Understand the pros and cons of genetic testing so you can make an informed decision about whether or not genetic testing is right for you and your family.
- Find out if your cancer diagnosis is caused by Lynch syndrome.
- Understand what Lynch syndrome is and what it means for you and your family.
- Assess your risk for other cancers and if you need other screening tests.
- Find out if your family members could have an increased risk for cancer.

## What other genetic testing could I get?

We use a blood test to diagnose Lynch syndrome.

## How can I prepare for my Genetics appointment?

- Talk to your family members to find out who else in your family has had cancer. **Complete the family history questionnaire you got at your referral and hand it in as soon as you can.**
- Write down questions to ask your genetic counsellor.
- Take a friend or family member to your appointment. Sometimes it is hard to remember all the information you get during the appointment.

## What happens after my appointment?

You and your health care provider will decide the next best steps for you based on your situation, history, and test results.

After your appointment, if you are diagnosed with Lynch syndrome:

- Specific screening tests would be recommended to help with early detection and prevention of some cancers.
- It may be important for your family members to be referred to a Genetics clinic.

## What supports are available?

Knowing you or your family members may be at increased risk of cancer can be very stressful. There is help and support with decision-making about genetic testing, coping and discussing these concerns with family members. Ask your health care provider for information on psychosocial support services.

## Where can I find more information?

- AHS cancer resources: <http://www.albertahealthservices.ca/cancer/>  
Click: Patient Information for a list of resources in your area
- Information on Lynch syndrome: Lynch Syndrome International - [www.lynchcancers.org](http://www.lynchcancers.org)
- Talk to your health care provider if you have any questions or concerns.

