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Lynch Syndrome

What is Lynch Syndrome?

Lynch syndrome, also called hereditary nonpolyposis colorectal cancer (HNPCC), is an inherited condition that increases your risk of getting cancer, especially colon cancer. It is estimated to cause 2 – 5% of all cancers in the colon and rectum (colorectal cancer) and is especially common in people who develop colorectal cancer before the age of 50.

The syndrome is divided into Lynch Syndrome I, or familial colon cancer, and Lynch Syndrome II, which is associated with other types of gastrointestinal (GI) cancers or cancers of the reproductive tract. People with Lynch syndrome not only have an increased risk of colorectal cancer but also an increased risk of cancers of the stomach, small intestine, liver, gall bladder ducts, upper urinary tract, skin, and for women, cancer of the ovaries and uterine lining.

However, just because you have Lynch syndrome doesn't mean that you are going to develop a cancer, but you do have a much higher than normal risk of getting cancer. It is estimated that 70% of people with Lynch syndrome will develop colorectal cancer by the age of 65. This highlights the importance of regular cancer screening if you have Lynch syndrome and the need to closely follow your doctor's recommendations for screening.

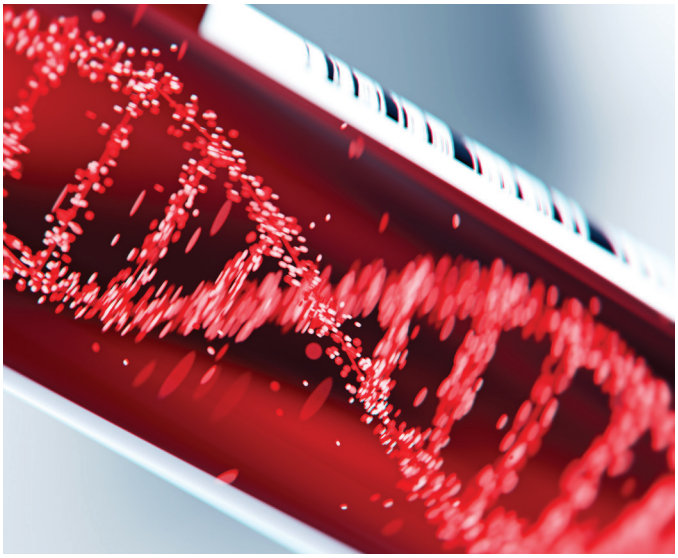
What Causes Lynch Syndrome?

Lynch syndrome is caused by abnormal changes, or mutations, in your genetic material, or genes. Each person has about 20,000 genes that are each made up of DNA that you inherited from your parents when you were conceived. Currently, there are 5 different genes that are known to be linked to Lynch syndrome. A mutation in any one of these genes can be passed to you from one of your parents, causing you to have Lynch syndrome.

If you have one of these gene mutations, your body loses its ability to repair damage to your DNA that naturally occurs throughout your life. This leads to the increased risk of cancer.

How is Lynch Syndrome Diagnosed?

Lynch syndrome does not cause any symptoms unless you develop a cancer that is linked to the syndrome. If you develop colorectal cancer, regardless of how old you are at the time of diagnosis, your doctor will offer you genetic testing for Lynch syndrome.



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Additionally, any of the following may be a signal to your doctor that you could have Lynch syndrome:

- a close relative has been diagnosed with Lynch syndrome
- family history of colon cancer that occurs before the age of 50
- strong family history of uterine, or endometrial, cancer
- strong family history of any of the other cancers associated with Lynch syndrome (listed above)

If your doctor suspects that you are at risk for Lynch syndrome, you will be referred to a genetic counselor to discuss your screening options. The counselor will review your family history and determine if there is a chance that you could have this condition. They will also review the testing process with you and the implications of the test. If you decide to be tested, you can be checked for the Lynch syndrome gene mutations using a blood or saliva test. After the test, it usually takes a few weeks before you receive the results.

How is Lynch Syndrome Treated?

Lynch syndrome is not curable. The main benefit of knowing that you have the syndrome is to allow your doctor to monitor you very closely for cancers that are associated with it, like colorectal cancer or urinary tract cancer. Ideally, cancers like colorectal cancer can be prevented through regular screening and by removing areas, such as polyps, that could potentially become a cancer. If a cancer is found, the hope is to diagnose it early, when only minimal treatment is needed.

There isn't a well-established cancer screening protocol for patients with Lynch syndrome, so you will need to work with your doctor to decide what is best for you and your situation. Tests that are generally recommended are a colonoscopy every 1 to 2 years, annual monitoring for uterine and ovarian cancer, upper endoscopy every 2 to 3 years, and an annual urinalysis. Depending on your situation, more aggressive preventative treatment options may be considered, which includes surgery or daily medication.

The diagnosis of Lynch syndrome can make you feel powerless and scared, especially because it is not curable. Therefore, part of your treatment should also focus on improving these feelings, so it may be helpful to join a support group or talk with a counselor about your fears and concerns. Focusing on a healthy lifestyle that includes eating well, maintaining a normal weight, getting regular exercise, and not smoking is also important and can help you focus on areas of your health that you can control.

What is the Prognosis of Lynch Syndrome?

The long term prognosis of Lynch syndrome depends upon whether you are diagnosed with a cancer and, if you are, what stage the cancer is found in. Early diagnosis of Lynch syndrome and regular cancer screening can help reduce your risk of developing cancer and improve your long-term survival.

Where Can You Get More Information About Lynch Syndrome?

- **American Society of Colon and Rectal Surgeons**
  https://www.fascrs.org/patients/disease-condition/hereditary-colorectal-cancer-0
- **American College of Gastroenterology**
  http://patients.gi.org/topics/lynch-syndrome/
- **U.S. National Library of Medicine**
  https://ghr.nlm.nih.gov/condition/lynch-syndrome
- **Lynch Syndrome International**
  https://lynchcancers.com/

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