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Lynch Syndrome

What is Lynch syndrome?

Lynch syndrome is a condition that increases the chance of getting some types of cancer. But not everyone who has it gets cancer. Lynch syndrome is caused by a mutation passed down from a parent. Boys and girls have the same chance of inheriting the mutation. If they inherit the mutation, they inherit the syndrome. And they are at increased risk for getting cancer.

Cancers caused by Lynch syndrome

Colorectal cancer (CRC) is the most common kind of cancer caused by Lynch syndrome. Lynch syndrome not only causes CRC, it also causes people to get it at a younger age. The chance of getting it is 52% to 82%.¹ But people without the syndrome have only a 4.8% chance.¹

Lynch syndrome also causes people to get other cancers at a younger age. The risk for getting these cancers is shown below.

Cancer Type	Cancer Risk (%) ⁴
Colorectal	52-82
Endometrial	25-60
Stomach	6-13
Ovarian	4-12
Small bowel	3-6
Sebaceous neoplasm	1-9
Hepatobiliary	1-4
Urinary tract	1-4
Brain/CNS	1-3

CNS, central nervous system.

Who should be screened for Lynch syndrome?

The guidelines recommend screening²:

- People with CRC
- People without CRC who:
 - Have a family history of Lynch syndrome
 - Had endometrial cancer before age 50



Additional Information

You can find more information about Lynch syndrome at these Web sites:

- Centers for Disease Control and Prevention: cdc.gov/Features/LynchSyndrome/
- Cancer.net: cancer.net/cancer-types/lynch-syndrome
- Lynch Syndrome International: lynchcancers.com/

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Why it's important to be screened

There are 2 important reasons to be screened. First, if you know you have Lynch syndrome, you can take steps to lower your risk of getting cancer. This is true even if you already have cancer. You can reduce your risk of getting the other types of cancers linked to Lynch syndrome.

Second, you can help protect your family's health. Lynch syndrome runs in families. So if you have it, your blood relatives are at risk. This means your mother, father, sister, brother, or children could have it too. If you tell them you have it, then they can get screened. If they have it, they too can take steps to protect their health.

How screening is done

Screening is done by testing either cancer tissue or blood. If you have a type of cancer that can be caused by Lynch syndrome, screening can be done on the cancer tissue. The screening tests used are:

- Microsatellite instability (MSI) test
- Immunohistochemical (IHC) test

If you don't have cancer, screening can be done on blood. The blood test shows if there is a mutation (change in your gene) that causes Lynch syndrome.

What if I find out I have Lynch syndrome?

People with Lynch syndrome can take steps to lower their chances of getting cancer. And they can try to be sure that any cancers are detected early. Treatment is more successful when cancer is detected early.

For example, there is a test to help prevent CRC or catch it early. It's called a colonoscopy. People with Lynch syndrome should have one every 1 to 2 years.³ And they should start around age 20 or 25.

Some doctors suggest looking at a sample from the endometrium every year.^{2,4} An ultrasound could be done too. The most important thing is to watch out for abnormal vaginal bleeding or spotting. This is a sign of endometrial cancer.

Your doctor can help you decide what steps to take.

References

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