Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Managing Lynch Syndrome

This information will help you manage Lynch syndrome. Lynch syndrome used to be called hereditary nonpolyposis colorectal cancer syndrome (HNPCC).

About Lynch Syndrome

Lynch syndrome is a condition caused by hereditary mutations in your genes. A hereditary mutation is a gene change that one or both of your parents passed down to you before you were born. These genes normally help prevent cancers. Lynch syndrome causes these genes to stop working, increasing your risk of getting colorectal, endometrial, and other cancers.

What's my risk for cancer if I have Lynch syndrome?

Lynch syndrome increases your risk of:

- Getting cancer at an early age.
- Having more than one type of cancer in your lifetime.

Your cancer risk may depend on which mutated gene is causing Lynch syndrome in your family. The type of cancer and the age at which you may get it is different for

everyone who has Lynch syndrome, even people in the same family. Having Lynch syndrome doesn't mean you'll definitely get cancer in your lifetime. It means you have an increased risk of getting certain types of cancers.

Colorectal and endometrial (uterine) cancer are the most common cancers linked to Lynch syndrome.

You may also be more likely to get other cancers, but this is less common. Examples of less common cancers linked to Lynch syndrome are:

- Ovarian cancer
- Stomach cancer
- Urinary tract cancer, which is cancer in the system of organs that make urine (pee) and drain it from your body
- Small bowel cancer, which is cancer in your small intestine. Your small bowel is a long tube that takes digested food from your stomach to your colon (large intestine).
- Pancreatic cancer
- Hepatobiliary tract cancer, which is cancer in the cells of the liver, bile ducts, and gallbladder
- Brain cancer

- Sebaceous carcinoma (cancer in the glands in your skin that make oil)

What's the recommended cancer surveillance plan for people with Lynch syndrome?

In general, the best way to protect yourself from cancer is to have regular cancer screenings. This is called a cancer surveillance plan. Following a cancer surveillance plan helps you and your healthcare providers notice the cancer as soon as possible after it develops, while it's easier to treat.

The following information is not a cancer surveillance plan. It's general information about common ways to screen for cancers linked to Lynch syndrome. It's very important to talk with your healthcare provider to create a cancer surveillance plan based on your individual needs.

Colorectal cancer

There are several ways to screen for colorectal cancer. They include:

- Getting a colonoscopy every 1 to 2 years.
- Looking out for the following:
  - Bleeding from your rectum.
  - Blood in your stool (poop) or in the toilet after having a bowel movement (pooping).

- Prolonged diarrhea (loose or watery bowel movements) or constipation (having fewer bowel movement than usual).
- Pain in your lower stomach. This might feel like you have to have a bowel movement when you don't need to.

Your healthcare provider may recommend you take aspirin. Aspirin isn't safe for everyone, don't start taking aspirin unless your healthcare provider instructs you to.

Endometrial cancer

There are a few ways to screen for and reduce your risk for endometrial cancer. They include:

- Looking out for any changes in your menstrual cycle (monthly period), such as more or less bleeding or more pain than usual.
- Getting an endometrial biopsy every 1 to 2 years.
- Having a hysterectomy (surgery to remove your uterus) and a bilateral (on both sides) salpingo-oophorectomy (surgery to remove your ovaries and fallopian tubes).

Ovarian cancer

There's no effective screening test for ovarian cancer. Instead of screening for ovarian cancer, talk with your healthcare provider about risk-reducing treatments. Risk-reducing treatments for ovarian cancer include:

- Taking a combined oral contraceptive (birth control pill with estrogen and progestin).
- Having a bilateral salpingo-oophorectomy (surgery to remove your ovaries and fallopian tubes).

You should also look out for:

- Any unusual bloating.
- Swelling in your abdominal (belly) area.

Pancreatic cancer

Generally, you don't need to screen for pancreatic cancer unless one of your family members has had it. If any of your family members have had pancreatic cancer, talk with your healthcare provider.

Stomach cancer

There are some ways to screen for stomach cancer, but these recommendations aren't for everyone. It's important to talk with your healthcare provider to create a cancer surveillance plan based on your individual needs. Your healthcare provider may recommend you have an upper

endoscopy every 3 years. You may need to have these more or less often depending on your results.

Small bowel cancer

Generally, you don't need to screen for small bowel cancer unless one of your family members has had it. If any of your family members have had small bowel cancer, talk with your healthcare provider. They may recommend you have a magnetic resonance imaging (MRI) or computed tomography (CT) enterography (imaging test to look at your small intestine) done every 3 years.

Urinary tract cancer

Screening for urinary tract cancer includes:

- Having a urinalysis (test to look for blood in your urine).
- Having a urine cytology (test to look for cancer cells in your urine).

If any of your family members have had urinary tract cancer, talk with your healthcare provider.

Skin cancer

Some people with Lynch syndrome may have an increased risk for a type of skin cancer that affects your sweat glands. If any of your family members have had this type of cancer, your healthcare provider may recommend you have your skin checked every month.

It's also important to follow general skin care guidelines, including:

- Looking out for any unusual skin changes, such as:
  - New moles or skin lesions.
  - Changes in a mole or skin lesion's shape, color, size, or texture.
- Trying not to spend too much time in direct sunlight.
- Protecting yourself from the sun when you're outside (such as by wearing hats, using sunscreen, and wearing sun-protective clothing).
- Visiting a dermatologist (skin doctor) for a skin exam every year.

What else can I do to lower my risk of getting cancer?
Following a healthy diet, getting enough exercise, quitting smoking, and reducing the amount of alcohol you drink can help you stay healthy and lower your risk of getting cancer. Talk with your healthcare provider for recommendations to help improve your lifestyle.

About MSK CATCH

Having Lynch syndrome means you're at high risk for cancer. It's important that your healthcare team is highly experienced at managing hereditary cancer risk. MSK

CATCH is a clinic for people living with a hereditary cancer syndrome such as Lynch syndrome. Our name stands for Comprehensive Assessment, Treatment, and Prevention of Cancers with Hereditary Predispositions, and we're here to be your partner in managing your Lynch syndrome while helping you live your best life.

You're only eligible for MSK CATCH if you've already had genetic testing and counseling, so we know surveillance is right for you. To learn more about MSK CATCH, talk with your healthcare provider or read *MSK CATCH: Expert advice on hereditary cancer syndromes* (www.mskcc.org/pe/msk-catch).

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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