



# FRANKLY SPEAKING ABOUT CANCER

## Lynch Syndrome

### Understanding Lynch Syndrome

Certain cancers can run in families. Sometimes this happens because of harmful changes (called mutations) in our genes that are passed from one generation to the next.

Lynch Syndrome is an inherited disorder. It is thought to be caused by certain genes that do not work as they should. Normally, these genes (called mismatch-repair genes) act like a spell check for the cells – catching and correcting any mistakes or errors. But, if there is a mutation in a specific gene, errors can accumulate in the cells. Over time, these cells can become cancerous.

Lynch Syndrome increases a person's risk of developing several types of cancer, including colorectal, endometrial (uterine), ovarian and stomach. That's why if you or other people in your family have been diagnosed with any of these cancers – especially at a young age – your doctor may talk with you about getting genetic counseling and testing for Lynch Syndrome.

*“While I can't control my genetics, I can control the steps I take for prevention.”*

— Ripley B.

Finding out you have Lynch Syndrome can be upsetting. It's normal to feel overwhelmed. There is a lot of complex information to digest; what does this mean for you, what does it mean for your family members?

But knowing that you have this condition can help you make better medical decisions – even if you are currently in cancer treatment or are a survivor. Together, you and your health care team can develop a plan to try to prevent or find Lynch-related cancers early, when they are most treatable.



#### Lynch Syndrome Facts, Support & Resources

Cancer Support Community

Fight Colorectal Cancer

MedlinePlus [search: Lynch Syndrome]

The National Society of Genetic Counselors

[cancersupportcommunity.org](http://cancersupportcommunity.org)

[FightColorectalCancer.org](http://FightColorectalCancer.org)

[medlineplus.org](http://medlineplus.org)

[nsgc.org](http://nsgc.org)



# What cancers are tied to Lynch Syndrome?

There are five genes related to Lynch syndrome (MLH1, MSH2, MSH6, PMS2, and EPCAM). The cancer risks and options for managing your or a loved one's risk will depend on which gene has a mutation.

People with this Syndrome are much more likely to develop:

- Colorectal cancer
- Endometrial cancer
- Ovarian cancer
- Stomach cancer

Lynch Syndrome has also been tied to urinary/renal, small bowel, pancreas, and brain cancers, but these are much less likely.

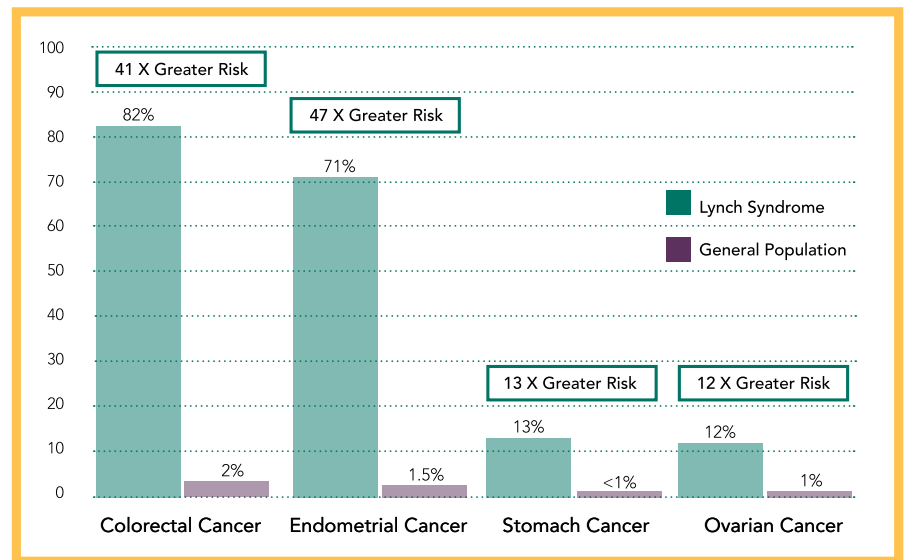
If you or someone in your family has Lynch Syndrome, you may be more likely to develop multiple cancers and often at younger ages.

The good news is that there are options to help manage your cancer risks.

## Some Facts about Lynch

- Someone with Lynch Syndrome has up to an 80 percent chance of developing colorectal cancer over their lifetime.
- Up to 5 percent of colorectal cancers are due to Lynch Syndrome.
- If someone has Lynch Syndrome, the odds are 50/50 that their children, brothers or sisters also have it.

## Lynch Makes Specific Types of Cancers Much More Likely



# Finding out if you have Lynch Syndrome

There are several ways you might find out that you or a family member has Lynch Syndrome.

If you have a personal or family history of Lynch-related cancers, you might decide to seek genetic counseling, or your doctor may recommend it. A genetic test on a sample of your blood can tell if you have a mutation.

If you already have colorectal cancer, screening tests might be done on the tumor itself as part of your initial diagnosis or treatment. If the results of either test are abnormal, it usually serves as a red flag to prompt further evaluation and genetic counseling.



# Benefits of Genetic Counseling

A genetic counselor – someone with special training in cancer and genetics – can help assess your personal and family history of cancer, and discuss which genetic test might be most appropriate for you or your family, and which relatives.

Your genetic counselor will likely want to know:

- Who has had cancer in your family (whether they are on your mother’s and/or father’s side)
- At what age they were diagnosed
- Where the cancer first started and a copy of the pathology report, if available
- If they are still alive
- If anyone in your family has already had genetic counseling or testing

*“Genetic testing for Lynch syndrome is so important – it can save lives.”*

— Heather Hampel, MS, CGC,  
Fight Colorectal Cancer Medical  
Advisory Board Member

Your genetic counselor will also help explain what the results mean for you based on which specific gene is involved. Not every gene associated with Lynch carries the same risk; nor are the results black and white – they must be considered in light of your personal and family history. Your counselor can also walk you through recommendations for screening and options to help reduce your cancer risks. If you have cancer, your treatment can be further tailored for you based on your genetics.

During this process, many people find it helpful to seek additional support. You might consider speaking to other people who have a similar genetic mutation. Support groups and/or mental health professionals can help you sort through your feelings and medical choices.



# Who should consider genetic testing

You should consider genetic counseling if any of the following conditions apply to you or your family:

- Colon or endometrial cancer diagnosed before 50
- Several cases of colon, endometrial or ovarian cancer on the same side of the family
- Multiple and/or early-onset colon polyps
- Multiple primary colorectal and/or related cancers in one individual (for example, colon and endometrial or colon and ovarian)
- Any Lynch Syndrome-related cancer or a tumor with an abnormal result on standard screening tests
- Known genetic mutation in the family

*“It’s not exactly fun to live through multiple cases of colorectal cancer and be high risk for others. But I do feel blessed knowing that I have it.”*

— Person with Lynch Syndrome



# Moving Forward

You found out that you or a loved one has Lynch Syndrome. So now what?

Fortunately, there are a number of options that can help manage your risk of certain cancers. It’s often a very personal choice.



# Reducing your risk

There are recommended steps to screen for Lynch-related cancers and/or medically reduce your risk of developing certain cancers. It's important to talk with your health care provider about the pros and cons of each option, and how each could affect your life.

CANCER TYPE	SCREENINGS	REDUCING YOUR RISK
COLORECTAL AND SMALL BOWEL/STOMACH	<p>Colonoscopy – a test that allows your doctor to see the inside of your colon – every 1-2 years starting in someone's 20s</p> <p>Upper endoscopy – a test to look into your throat and stomach – every 2-5 years starting at 30-35 years of age</p>	<p>Preventive surgery to remove any polyps</p> <p>More extensive surgery may be considered if you have had colon cancer, but should be carefully considered with your doctor's input</p> <p>Treatment of infections, such as H-pylori</p> <p>Nonsteroidal anti-inflammatories, including aspirin, may reduce colorectal cancer risk; however, data are limited.</p>
URINARY TRACT	<p>Yearly exam of your urine (urinalysis) starting at age 30-35</p>	
OVARIAN/ENDOMETRIAL	<p>By age 30-35, screening would include annual</p> <ul style="list-style-type: none"><li>• Transvaginal ultrasound</li><li>• Endometrial biopsy</li><li>• CA125 tumor marker blood testing</li></ul>	<p>Preventive (prophylactic) removal of the uterus, ovaries and fallopian tubes by age 35, or once a woman is done having children</p> <p>Birth control pills, although it is unclear how effective this is among women with Lynch syndrome</p>

Take the time to think through each option before deciding what is right for you. Try not to feel pressured to make any decisions quickly. Talk with your health care provider about how much time you can reasonably take to fully process the information before making decisions.

*“Lynch Syndrome is fairly rare. But for an individual who has it, it dramatically changes the way their health should be managed, and makes them candidates for screening and risk reduction options they wouldn't normally be offered.”*

— Danielle Bonadies, MS, genetic counselor at the Yale Cancer Center



## Common concerns

Living with Lynch Syndrome can cause anxiety and ongoing concerns. These may include:

- **Ongoing uncertainty** about what this means, especially due to the number of different cancers, what you and your family members might do with the information and if you even want to know.
- **Fears** that you are somehow damaged, or that cancer is already lurking in your body.
- **Concerns about how your body will be affected.** For example, how a hysterectomy will affect your plans to have children, your sex life, mood and risk for other health problems (heart disease, osteoporosis)?
- **Distress about when and how to tell your family.**
- **Feelings of guilt** that you might have passed a harmful gene onto your children.
- **Concerns that you won't be able to get affordable life or disability insurance** – the laws that protect against genetic discrimination do not extend to life and disability insurance.
- **Worries about the cost of care.** There are resources to help if you don't have insurance.
- **Anxiety about follow-up care, exams and recovery.** Additional surveillance, procedures and/or surgeries may be stressful. This might be related to the exams themselves or the time that appointments/prep/recovery may take, which can also interfere with work or caring for your family.



## Coping & Next Steps

Living with a potentially higher risk of cancer than others can create challenges that you have never faced before. Throughout the process, be true to yourself and know your limits and when you need to lean on others for support.

Some tips for coping:

- **Be empowered.** Knowledge is power, and you have options to stay on top of your future cancer risk.
- **Pace yourself.** Think about the one thing you need to do next, and ask for help if you feel overwhelmed.
- **Use your support system.** It's important to have at least one person you can lean on and talk to and who will not judge you as you make decisions. It may help to bring someone to your medical appointments too.
- **Use positive self-talk.** "One day at a time." "I will get through this."
- **Keep up healthy routines.** Exercising, eating well and doing things that make you happy can help reduce stress and keep you going no matter where you are on the spectrum from testing to treatment.
- **It's ok to have conflicting feelings.** There will be good and bad days, and it's ok to feel upset. If you are having difficulty, you may want to seek counseling.
- **Keep any follow-up medical visits.** Be sure to tell your health care provider if anything has changed.
- **Give your partner or spouse permission to feel too.** Let them know what they can do to help support you.
- **Seek counseling or support if you need it.** See the back page for a list of resources.

*"Most people are resilient. Certainly there can be shock at first, but you gradually feel like you can do this."*

— Karen Hurley, PhD,  
psychologist



# Questions to Ask

- What is the right genetic test(s) for me?
- How long will it take to get the results?
- How much does genetic testing cost?
- Will my insurance cover genetic testing and genetic counseling?
- If I have Lynch, how will it affect me/my future health?
- How will it affect other people in my family?
- What specific gene is affected?
- What types of cancer screening can detect Lynch-related cancers?
- When and how should I tell my family?
- When is the right time to consider medications or surgery?
- What laws will protect me from genetic discrimination?

WWW.CANCERSUPPORTCOMMUNITY.ORG 888.793.9355

## VALUABLE RESOURCES

Help is available to you and your loved ones.

### CSC Resources for Support

#### Cancer Support Helpline® 1-888-793-9355

Our free helpline is open Monday – Friday 9:00 am – 8:00 pm ET. Anyone impacted by cancer can call to talk to a call center counselor. We will connect you with local and national resources, and help you find the right support.

#### Frankly Speaking About Cancer®

CSC’s cancer education series, providing sound educational and psychological information for cancer patients and their loved ones.

#### Affiliate Network

Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost.

All of these services are made available with generous contributions from CSC supporters. **To access these services, visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call 1-888-793-9355.**

### Other Resources and Support

Fight Colorectal Cancer

[FightColorectalCancer.org](http://FightColorectalCancer.org)

MedlinePlus [search: Lynch Syndrome]

[medlineplus.org](http://medlineplus.org)

National Cancer Institute: Cancer Genetics Services Registry

[cancer.gov/cancertopics/genetics/directory](http://cancer.gov/cancertopics/genetics/directory)

The National Society of Genetic Counselors

[nsgc.org](http://nsgc.org)



The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.



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