LYNCH SYNDROME: FREQUENTLY ASKED QUESTIONS ABOUT A NEW DIAGNOSIS

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LYNCH SYNDROME

If you have been recently diagnosed with Lynch syndrome, you may have questions regarding screening and prevention. Below are some answers to common questions about healthcare for people with Lynch syndrome.

YOUR LYNCH SYNDROME DIAGNOSIS

What are the cancers I am at risk for developing?

Lynch syndrome is a condition that increases your chance of developing certain types of cancers. Your exact cancer risks vary depending on factors like your family history of cancer, age, personal cancer history, and your specific mutation. Talking to your healthcare providers about your diagnosis of Lynch syndrome and the types of cancer associated with the condition is the first step in making sure you are getting the best healthcare possible related to your diagnosis.

Lynch syndrome cancer risk

Cancer	General Population Risk	Syndrome Risk (depends on mutation)
Colorectal	5.5%	10-80%
Endometrium	2.7%	15-60%
Ovary	1.6%	4-24%
Stomach	<1%	1-13%
Pancreas	<1%	1-6%
Small bowel	<1%	3-6%
Hepatobiliary tract	<1%	1.4-4%

How will my diagnosis affect my life?

People react to a new diagnosis of Lynch syndrome in different ways. While some feel anxious about the diagnosis, others feel empowered by the information. Everyone with Lynch syndrome should learn about and follow recommended screening guidelines. Resources such as support groups, genetic specialists (genetic counselors and genetic doctors), and other specialists knowledgeable about Lynch syndrome can help you adjust to your new diagnosis.

YOUR FAMILY AND LYNCH SYNDROME

How does this diagnosis affect my family i.e. who else should be getting testing or screening?

Lynch syndrome is a genetic condition that is inherited from one of your parents. Thus, siblings and your children each have a 50% chance of having the same Lynch syndrome mutation you have. Other relatives, such as cousins, aunts, and uncles, are also at-risk. It is important to let these relatives know about the diagnosis of Lynch syndrome in the family. If possible, it is also important to share your specific test results with them. If they wish to get testing, this ensures that that the correct genetic testing is done.

How do I tell my relatives about Lynch syndrome?

Talk to your physician or genetic counselor about ways to discuss Lynch syndrome with your family. Genetic counselors often provide letters and other resources to help people inform their family members. Also, talk to your close family members about the best way to share this information with others in the family.

What screening should be done for relatives that choose not to get genetic testing?

Individuals who choose not to undergo genetic testing can still qualify for high-risk screening. They should speak with their healthcare providers about their best screening plan options and be followed as though they have Lynch syndrome.

I'm considering starting a family…

What factors should I consider in regards to reproductive decisions?

Lynch syndrome is associated with an increased risk for both uterine and ovarian cancers. Screening for these types of cancers has been shown to be less effective. Therefore, current guidelines indicate that women should consider risk-reducing hysterectomy and bilateral salpingo-oophorectomy (removing the uterus, ovaries, and fallopian tube) once they have finished having children.

What factors should I consider with regard to risks to my future children?

For parents that do not want to have a child at risk for Lynch syndrome, one option is preimplantation genetic diagnosis (PGD). This procedure identifies mutations and uses in vitro fertilization (IVF) to prevent certain conditions from being passed on to children.

SCREENING, PREVENTION, AND TREATMENT OPTIONS

At what age should I begin screening?

Current guidelines recommend that individuals at risk for or affected with this condition begin screening for colon cancer by colonoscopy beginning between ages 20 and 30 years old. Colonoscopies should be performed every 1-2 years. The age to begin screening for colon cancer can differ depending on your personal family history.

Does my family history of specific cancers affect the screening procedures I undergo?

Individuals may have a strong family history of a particular type of cancer. If you are concerned about a specific type of cancer, it is important to discuss with your healthcare team about the risks and-risk reducing options available. For example, some individuals with Lynch syndrome have a strong family history of breast cancer and need increased surveillance.

What are the best preventative measures for me to consider?

Screening and management options, including surgical intervention, are recommended for individuals with Lynch syndrome due to their increased cancer risk. Your primary care provider should follow national guidelines (see references) in developing your management plan.

If I am considering preventative surgery, when should I do it?

Surgical intervention is an option to consider. Total abdominal hysterectomy with bilateral salpingo-oophorectomy (removal of uterus, fallopian tubes, and ovaries) is an option for women who are done having children.

Are there any risks to these risk-reducing procedures?

Medical procedures can have several risks. Your healthcare provider should discuss these risks with you prior to performing the procedure. Also consider downloading the free booklet "Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource" from Fox Chase Cancer Center (http://www.igcs.org/professionalEducation/RiskReductionSurg.html).

What lifestyle changes should I consider making?

Diet and exercise has been shown to reduce the risk of developing cancer. Daily aspirin has been suggested to be able to reduce risk of colon cancer. However, discuss this with your provider to ensure this is the best option for you.

If I am diagnosed with cancer, would my treatment plan be different since I have Lynch syndrome?

Because of specific Lynch syndrome mutations, there is a risk of a second primary cancer developing in the same site in the body or a new site. This risk may affect your course of treatment, i.e. some forms of chemotherapy may be less beneficial.

INSURANCE IMPLICATIONS

Is insurance going to cover my genetic testing or screening for cancer?

Coverage of genetic testing and screening varies depending on your insurance. Contact your insurance company to learn more.

What laws protect me from genetic discrimination?

Genetic Information Nondiscrimination Act (GINA) is a federal law that prevents discrimination from health insurance and employers due to genetic information. Employers cannot terminate or refuse compensation based on this information and insurers cannot raise rates. However, this law does not cover those who already have cancer and no laws exist that cover life insurance or long-term disability insurance. If you want these policies, they should be acquired before genetic testing is done. More information about GINA can be found here: http://ginahelp.org/.

Please contact your healthcare team for more details or if you have any additional concerns.

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