



NHS

RM Partners
West London Cancer Alliance
Formed by The Royal Marsden NHS Foundation Trust



QUESTIONS

Q&A

LYNCH SYNDROME

1. IF I HAVE LYNCH SYNDROME WILL I GET CANCER AGAIN?

It is possible because one of the body's systems that gets rid of damaged cells are not working properly. There are certain cancer types that people with Lynch syndrome are more at risk of getting, like bowel, or womb cancer.

2. WHAT CAN I DO TO REDUCE MY RISKS OF FURTHER CANCER?

Try and live a healthy lifestyle, maintain healthy body weight, eating good food, exercising, not drinking too much alcohol and not smoking. Taking aspirin can also reduce the risk, but please talk to your doctor first. Also having high fibre diet with resistant starch (e.g. firm banana a day) can reduce the risk of upper GI cancers in particular.

3. WHAT SCREENING WILL I BE OFFERED TO PROTECT MY FUTURE HEALTH?

Two yearly check-up on your bowel (this might start from the age of 25). It is very good idea to become aware of the signs and symptoms of skin, gynaecological and bowel cancers so if you are worried, you can immediately go to the doctor's. There is also a one-off screening for Helicobacter pylori. This is a bacteria that 30% of the population have in the stomach. Removing this bacteria may reduce the likelihood of stomach cancer.

4. HOW DOES IT AFFECT MY FAMILY?

Half of our genes and DNA, come from our mother, and half come from our father. If our mother or father has a gene that doesn't work, they can pass this gene on to their children. This means their children has 50% chance of getting the damaged gene, so they are at risk of getting cancer.

Your parents, siblings, and children have 50% chance of also having Lynch syndrome. They will need to know this information so they can take steps to protect themselves against cancer.

Ask your CNS and they can show you where to find support to help you talk to your family.

5. CAN IT SKIP GENERATIONS?

No. Lynch syndrome does not skip generations, but it does not necessarily mean your child will get Lynch syndrome (there is a 50:50 risk of inheriting Lynch syndrome). Remember not everyone with Lynch will get cancer.



6. WHO SHOULD I TELL THAT I HAVE LYNCH SYNDROME?

It is important that you tell your parents and siblings about your diagnosis, as they have a 50% chance of having Lynch syndrome. Knowing this information can help them to take steps to prevent or reduce their risk of developing cancer.

If you have children, they also have a 50% chance of having Lynch syndrome. Deciding how and when to have this conversation can be difficult. This will depend on their age but most children cope better when the family is open and honest about what is happening. Genetic testing for children is offered from age of 18.

REMEMBER THAT NOT EVERYONE LIVING WITH LYNCH SYNDROME WILL DEVELOP CANCER.

If you are planning to have children and you have a confirmed Lynch syndrome diagnosis, you can be offered prenatal genetic testing and the chance to discuss other options. Ask your doctor for more information.

7. HOW DO I EXPLAIN IT?

It is important to remember that you are not responsible for having Lynch syndrome. It can be good to rehearse what you want to say. You could start talking about:

- Genes being inherited, even the ones that do not work properly
- What Mismatch proteins are, and why they are important in keeping us healthy
- That cancer can happen when cells become damaged, and how Mismatch repair proteins get rid of these damaged cells and protect us from cancer
- How the genes that make Mismatch proteins can sometimes not work properly, and when this happens a person might have Lynch syndrome

8. WHERE CAN I GET MORE SUPPORT?

www.lynch-syndrome-uk.org