Cambridge University Hospitals NHS
NHS Foundation Trust

Family History of Bowel Cancer: Lynch Syndrome

Why have I been given this information sheet?

You have been given this information sheet because you have asked for advice about your family history of bowel cancer. This should accompany a letter from the Genetics service, which will have additional information and recommendations specific for your family.

How often is cancer hereditary?

Cancer is very common and 1 in 3 people in the general population are affected by some form of cancer during their lifetime. Most cancers do not have a strong hereditary cause. For a small proportion of families, however, a tendency to develop certain cancers may be hereditary. Sometimes, this is due to an alteration in a specific gene.

Lynch Syndrome

A hereditary condition called Lynch syndrome (also called Hereditary Non-Polyposis Colorectal Cancer, or HNPCC) can ***sometimes*** account for a family history of cancer. This condition mainly increases the risk of bowel cancer but may also increase the risk of womb cancer in women. Bowel cancer affects about one in 20 people in the general population (5%) and womb cancer affects about one in 100 (1%) women. For an individual with Lynch syndrome these risks may be 25 to 70% over a lifetime for bowel cancer and up to 30 to 70% for womb cancer. Occasionally, ovary, stomach, pancreas, kidney or urinary tract cancers have also been reported in families with Lynch syndrome. Investigating whether Lynch syndrome is responsible for cancers in a family usually involves examining a small sample of the tumour a relative had removed followed by analysis of Lynch syndrome genes to find a specific gene alteration (called a mutation).

Inheritance of Lynch Syndrome

Lynch syndrome is caused by mutation in one of 4 different genes (these are called MLH1, MSH2, MSH6 and PMS2). Genes are instructions that tell our bodies how to grow and function. We have two copies of every gene as we inherit one from each parent. Lynch syndrome is inherited in a 'dominant' fashion. This means that someone with Lynch syndrome has one mutated gene and one normal copy. Their children have a 50%, or 1 in 2, chance of having inherited the gene mutation and being at increased risk of cancer. They also have a 50% chance of not having the mutation.

Genetic testing for Lynch syndrome

Testing for Lynch syndrome can be offered to at-risk adult relatives (children, parent or sibling) of someone with a Lynch syndrome mutation. This is done through a local Genetics Service. It involves having a small blood sample taken and providing informed consent. At the moment there is a ban on insurance companies asking for the results of genetic tests (www.abi.org.uk)

Should I have bowel or other screening?

Individuals with Lynch syndrome may be referred for bowel screening by colonoscopy every 2 years from about age 25. Colonoscopy involves a thorough examination of your large bowel using a very small camera attached to a tube. This can detect small growths (polyps) which can be removed painlessly during the procedure. Polyps are usually harmless growths but some polyps can become cancerous if left in place for a long time. Women may also wish to be referred to a gynaecologist to discuss managing the risk of womb or ovarian cancer. Men and women with Lynch syndrome should be advised to see their GP for *Helicobacter pylori* infection screening and eradication from age 25 as this infection is a risk factor for stomach cancer.

What can I do to help my risk?

Maintaining a healthy diet, with plenty of fruit and vegetables, and not smoking, can help to minimise the risk of bowel cancer. You should also be aware of symptoms such as rectal bleeding, abdominal pain, and persistent change in bowel habit and bring these immediately to the attention of your GP. Research studies suggest that aspirin may reduce the risk of developing cancer in individuals with a Lynch syndrome mutation. However, further studies are needed to establish the optimum dose. We hope to gather this information via the CAPP3 study. If you would like further information or wish to participate in this study please contact: XXXXXXX. If you wish to take Aspirin 75 mg EC once daily pending recruitment or the results from the study please discuss this with your GP.

Dominant Inheritance