

Who is at increased risk of inheriting HNPCC?

People who may be at increased risk are those with:
Either at least three relatives on the same side of the family who have had colorectal cancer.
Or at least two relatives with colorectal cancer and at least one relative with uterine or ovarian cancer, all on the same side of the family.

In both situations, at least one of the colorectal cancers should have been diagnosed under the age of 50.

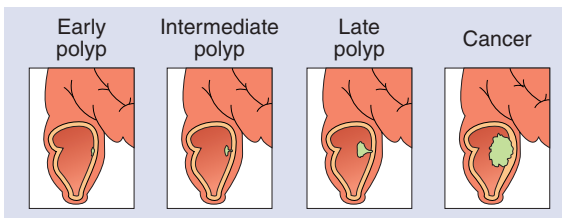
What can you do if you are at increased risk?

Sometimes we can do a blood test to find out if a person has inherited an altered hMLH1 or hMSH2 or hMSH6 gene. This test is only possible if we find that somebody in the family who has had colorectal, uterine or ovarian cancer has an altered hMLH1, hMSH2 or hMSH6 gene.

If you are at increased risk of cancer, but cannot be tested at present, you may still be able to have regular screening.

Colonoscopy screening: this is an internal examination of the large bowel, which uses a tiny camera to look for polyps. These are non-cancerous lumps that can grow inside the lining of the bowel.

Polyps are quite common in the general population, but they are more common in people with an inherited susceptibility to bowel cancer. Most polyps are harmless and will not cause any trouble. However, the occasional polyp may grow over many years and develop into a cancer, as illustrated below:



It should be possible to prevent a cancer from forming by removing polyps. Removal of polyps is usually carried out during a colonoscopy.

Ovarian screening: this involves an annual transvaginal ultrasound scan and a blood test.

Uterine screening: this involves an annual transvaginal ultrasound scan and endometrial sampling.

For more information:

If you need more advice about any aspect of inherited cancer, you are welcome to contact:

Clinical Genetics Departments

Northern Scotland (main base Aberdeen)

Tel: 01224 552120 Fax: 01224 559390

(Aberdeenshire, Moray, Highland, Western & Northern Isles)

Tayside (main base Dundee)

Tel: 01382 632035 Fax: 01382 645731

(Perth & Kinross, Angus, North East Fife)

South East Scotland (main base Edinburgh)

Tel: 0131 651 1012 Fax: 0131 651 1013

(Borders, Lothian, South West Fife)

West of Scotland (main base Glasgow)

Tel: 0141 201 0808 Fax: 0141 201 0361

(Glasgow, Argyll & Bute, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

If you need more advice about cancer and support groups, please contact:

www.maggiescentres.org

Maggies Highlands Tel: 01463 706302

Maggies Dundee Tel: 01382 496384

Maggies Edinburgh Tel: 0131 5373131

Maggies Glasgow Tel: 0141 330 3311

This leaflet was written by Guy's & St. Thomas' Clinical Genetics, updated 2003. Updated by Genetic Interest Group Scotland.

Hereditary Non-Polyposis Colorectal Cancer (HNPCC)

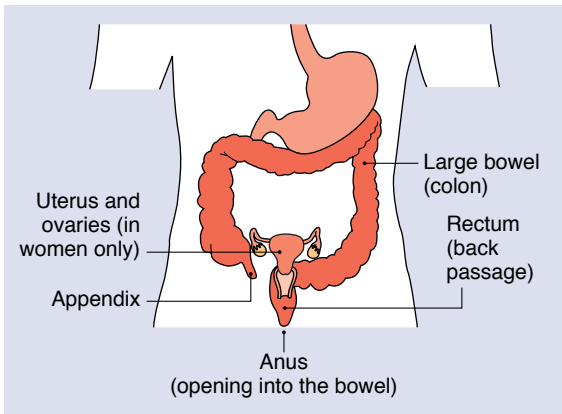


Information for people
attending the
Family Cancer Clinic

Seen in clinic by.....

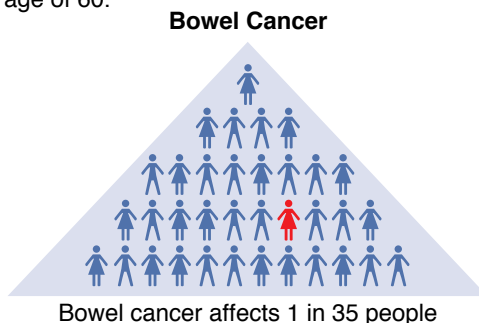
Introduction

HNPCC is an hereditary condition that causes people to have an increased risk of developing certain types of cancer. Men and women who have inherited HNPCC have an increased risk of developing colorectal cancer, which is cancer of the large bowel (colon) and rectum. Women who have HNPCC also have an increased risk of developing cancer of the womb (uterus) and ovaries. The diagram below shows the position of the large bowel and the rectum. The position of the uterus and ovaries are also illustrated.



How common is colorectal, uterine and ovarian cancer in the general population?

In the UK, colorectal cancer affects 1 in 35 people during their lifetime. Most of these people are over the age of 60.



What is "inherited" cancer susceptibility?

In a small number of families, close blood relatives over several generations have developed colorectal cancer, and some may have had uterine or ovarian cancer. These relatives may have an inherited gene alteration which makes them more likely to get these cancers.

What are genes?

Our genes are the unique set of instructions inside our bodies which make each of us individual. There are many thousands of different genes, each carrying a different instruction.

As well as determining how we look, our genes control the way each cell or "building block" of the body works. Specific genes control specific cells. Some genes are particularly important in controlling the way in which the cells in the colon and rectum, uterus and ovaries function and grow. We inherit two copies of each of our genes, one from our mother and one from our father.

Why do some genes increase the risk of cancer?

The instructions in each gene are like a code. Sometimes the code differs from that of a normal gene.

Imagine the code for a normal gene is:

1-2-3-4-5-6-7-8-9-10-11-12-13

The gene passed down through the family may have a slightly different code:

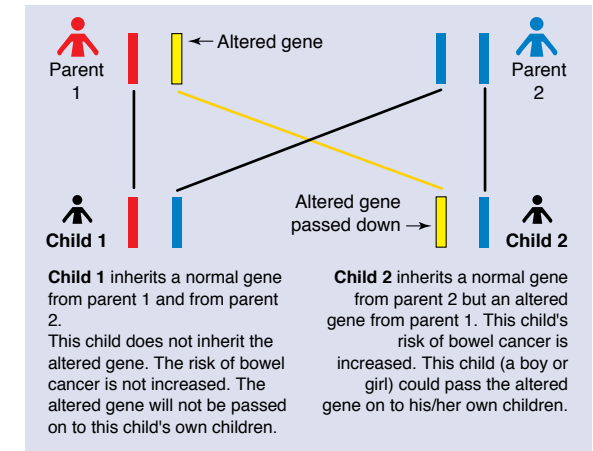
1-2-3-4-5-6-7-9-9-10-11-12-13

This gene will give slightly different instructions to the cells that it controls than a gene with a normal code. We call this an **altered gene**.

If the altered gene is one that normally controls the function and growth of colorectal, uterine and ovarian cells, there is a higher chance that cancer may develop in these areas.

How can an altered gene be inherited?

If one parent (either the mother or the father) has an altered gene, this can be passed down to a child. Each child has a 50/50 chance of inheriting that parent's altered gene and a 50/50 chance of inheriting that parent's normal gene. For example:



Which genes increase the risk of these cancers?

There are altered forms of three genes, hMLH1, hMSH2 and hMSH6, which are important in colorectal, uterine and ovarian cancer. There may also be other such genes that have not yet been discovered. A person who inherits an altered hMLH1 or hMSH2 or hMSH6 gene will not always get cancer, but:

- People with HNPCC may develop polyps in the bowel which may develop into cancer over time.
- A man or a woman will have a significantly increased chance of getting colorectal cancer during his/her lifetime (50-80%, lower in women than men).
- A woman will also have an increased risk of developing uterine cancer (up to 60%) and ovarian cancer (about 10%) in her lifetime.