NHS
Birmingham Women's and Children's
NHS Foundation Trust

Information leaflet for families with a history of bowel cancer or polyps

MYH Polyposis

What is MYH?

MYH is an inherited condition which causes people to be predisposed to developing bowel polyps and cancers.

What is a polyp?

A Polyp is a small non-cancerous growth.
Polyps usually occur in the colon (large bowel).
It is normal for an adult to develop 1 or 2 polyps as they get older but it is unusual to have lots of polyps. When lots of polyps occur we call this Polyposis.

Polyps are usually harmless. If they are left for several years some types of polyps can develop into cancers. If someone has lots of polyps, it is more likely that one of them might develop into a cancer.

Some people are more prone to developing lots of polyps because of an inherited condition. One of these conditions is called MYH, after the gene which causes it.

What is the MYH gene?

Genes are instructions which tell our bodies how to work. We each have about 20,000-25,0000 genes. All our genes come in pairs as we get one copy from our Mum and one from our Dad. Each gene has a specific job. The MYH gene is important in repairing damage to cells. If part of the gene is missing or altered, it will not be able to do its job properly. If this happens in the MYH gene, people can develop lots of polyps and so have a higher risk of bowel cancer.

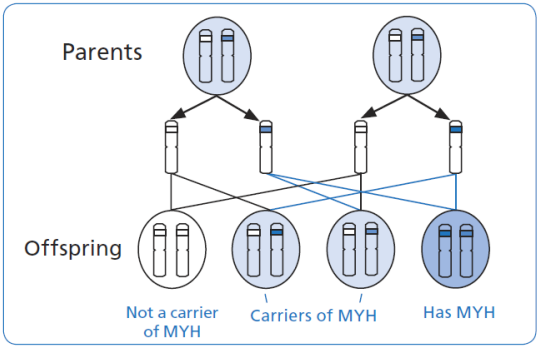
How does MYH run in families?

MYH is inherited in a way called autosomal recessive.

We each have two copies of the MYH gene.
It is only if we inherit an alteration in both copies of the gene that problems occur. Lots of polyps develop because there is no working copy of the gene.

People who have one altered and one working copy of the gene are carriers of MYH, but do not develop the condition themselves. This is because they still have a working copy of the gene which compensates for the altered one.

When a couple has a child they each pass on one copy of each gene at random. If both parents are carriers for MYH there are 4 possible combinations of the genes that the child may receive. This is shown in the diagram below.



Can you test for MYH?

It is possible to look at the MYH gene by taking a blood sample. If possible, it is best if this test is first done in someone who has had cancer or lots of polyps.

You may have been offered testing for MYH if :

- You have had between 5 and 100 polyps.
- There has only been one person in your family with bowel cancer diagnosed at a young age.
- There are several people with bowel cancer in your family and testing for all the known bowel cancer genes is undertaken at once.
- One of your close relatives is known to have MYH.

What happens next?

If the initial tests do not find any MYH alterations it is unlikely that MYH is the cause of the cancers or polyps in your family. We would not be able to offer testing to family members. They should continue with any bowel screening already recommended.

However, if tests show that MYH is the cause of the cancers or polyps in your family, it would be possible to offer genetic testing to other family members.

What does it mean for my relatives?

We would be happy to discuss genetic testing with other family members. Relatives living outside the West Midlands could also ask their GP to refer them to their local genetics service.

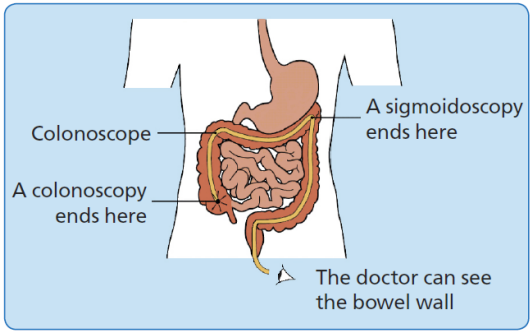
After testing, people who have alterations in both their MYH genes will need bowel screening every 2 years.

Family members who have only one altered copy of the MYH gene (carriers) are not thought to have a high enough risk for screening to be beneficial. Family members with two working copies of the gene have the same risk of bowel cancer as the general population.

In families with MYH, the risk for the next generation is often low, as the chances of both parents being carriers for MYH is small.

What does bowel screening involve?

To have a colonoscopy you must first empty the bowel by taking strong laxatives. A colonoscope is a long flexible tube containing a tiny camera (about the thickness of your index finger). It is passed through the anus and along the bowel to look for polyps or abnormalities. You will be given mild sedation so it is not usually too uncomfortable.



How the bowel is examined by colonoscopy

There are two benefits of the colonoscopies. Firstly, they are able to detect cancers early when they are more treatable. Secondly, during the procedure, any polyps found can be removed. This reduces the chances of cancers forming.

What symptoms should I look out for?

You should be aware of any persistent unexplained tiredness or any unusual bowel symptoms. This might include blood in your stools, passing mucus, unexpected weight loss or persistent change in bowel habits. You should ask your GP for further advice about these. You should make your doctor aware of the family history and may wish to take this leaflet with you.

If anyone else in the family develops any cancers or polyps please let us know so we can update our advice.

Further information

www.cancerresearchuk.org

www.macmillan.org.uk/Home.aspx

If you need more advice please contact:

West Midlands Family Cancer Service Clinical Genetics Unit
Birmingham Women's and Children's
NHS Foundation Trust
Mindelsohn Way, Edgbaston
Birmingham B15 2TG

Telephone: 0121 335 8024
Email: genetics.info@nhs.net

Birmingham Women's and Children's NHS Foundation Trust
Mindelsohn Way, Edgbaston
Birmingham B15 2TG

Author: Clinical genetics Unit
Reviewed date: June 2017
Next review: June 2020
Ref No: CG9