MUHYH Associated Polyposis Syndrome (MAP)

Information for patients

Nottingham Clinical Genetics

This document can be provided in different languages and formats. For more information please contact:

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Feedback
We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):
Freephone: 0800 183 0204
From a mobile or abroad: 0115 924 9924 ext 65412 or 62301
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR

www.nuh.nhs.uk

If you require a full list of references for this leaflet please email patientinformation@nuh.nhs.uk or phone 0115 924 9924 ext. 67184.

The Trust endeavours to ensure that the information given here is accurate and impartial.
This booklet has been written for people who have a personal or family history of MUTYH associated polyposis (MAP). It has been written for use with a clinical genetics appointment and should answer some of your questions. It may also help you share the information you receive with your relatives.

The gastro-intestinal tract

* Bowel in this case refers to the large intestine which is made up of the colon, rectum and anus

Is bowel cancer inherited?

Unfortunately bowel cancer is common in the general population. About 1 in 14 men and 1 in 19 women will develop bowel cancer at some point in their lives. Only a small proportion of bowel cancers are due to an underlying genetic susceptibility.
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 one or two polyps as they get older. It is unusual to have lots of polyps or develop them at a younger age and this may suggest an underlying genetic cause. When lots of polyps occur, we call this *polyposis*.

The pattern of bowel cancer and polyps in your family is due to a genetic (inherited) bowel condition called MUTYH associated polyposis (MAP).

What is a MAP?
MAP is a genetic (inherited) condition which causes people to be predisposed to developing bowel polyps and cancer.

What happens in MAP?
People with MAP develop a number of polyps. There are many different types of polyps but the polyps that tend to be seen with MAP are called adenomas. If left, adenomas may develop into a cancer.

What causes MAP?
Genes are the instructions that tell our bodies how to grow and function. MAP is caused by mutations (alterations) in a gene found on chromosome 1, the MUTYH gene. When this gene works as expected, it protects our large bowel. When there are mutations in the MUTYH gene, there is less protection and multiple polyps can develop in the large bowel and there is a higher risk of bowel cancer.
How is MAP inherited?
All our genes come in pairs and we inherit one copy from our mother and one copy from our father.

MAP shows a recessive pattern of inheritance. This means that for a person to have the risk of developing multiple polyps and bowel cancer, they need to have a mutation on both copies of their MUTYH gene.

A person who has a mutation in one copy of their MUTYH gene and one working copy of the gene is known as a carrier of the condition.

Can you test for MAP?
A person’s genes can be examined from a blood sample. However, because only a small proportion of people with bowel polyps and/or bowel cancer will have mutations, and because the test can be difficult to interpret, at present, genetic testing is only offered to the individual who has had bowel polyps or bowel cancer initially.

The team involved in your care are:
Consultant: .................................................................
Tel: ..........................................................................

Genetic Counsellor: ......................................................
Tel: ..........................................................................

Sources of further information
The Polyposis Registry
Level V, St. Mark’s Hospital
Northwick Park
Watford Road
Harrow
Middlesex
HA1 3UJ

Tel: 020 8235 4270
Email: LNWH-tr.polyposisregistry@nhs.net
www.polyposisregistry.org.uk

PolyPeople - Support Group
www.polypeople.online

Macmillan Cancer Support
Tel:0808 808 0000
www.macmillan.org.uk
**What about life insurance?**

For someone with MUTYH mutations who has been affected with MUTYH associated polyps/cancer

If you decide to take out a new policy insurance companies are entitled to ask if you have had a genetic test just as they may request other information about your treatment or surgery.

Someone who has mutations in MUTYH who has no evidence of bowel polyps or bowel cancer at this stage

Currently insurance companies are not allowed to ask about predictive genetic test results in unaffected individuals. Sometimes people will choose to disclose a MAP negative genetic test result to try to lower the premium of their policy which may be weighted due to their family history.

The Genetic Alliance have a patient leaflet relating to all aspects of insurance questions: [www.geneticalliance.org.uk/insurance](http://www.geneticalliance.org.uk/insurance)

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**Usually testing is a two-stage process**

The first step, the ‘diagnostic test’, looks for mutations in a person who has had multiple bowel polyps or bowel cancer. The results of diagnostic testing currently take up to 4 months. Diagnostic testing for MAP is often done alongside testing for other conditions that cause polyposis and bowel cancer.

**Genetic testing once MUTYH mutations have been found in a family**

If someone in your family is known to have MAP, you can now have a genetic test to see if you have inherited one or both of the mutations seen in them. This may be to see if you are at risk of having the condition or to see if you are a carrier of the condition and may be at risk of passing it on to your children.

Before we offer a test, we will meet with you to discuss what the test could mean for you and your family. At the clinic appointment we will help you to consider:

- How this test could affect you and your future
- If the result could impact on your employment or insurance
- Who you plan to talk to about your test and result
- Who we can share the result with
- How the test result could impact on your family, children and relationships.

The results are usually given face to face and are available around 4 weeks from having the blood sample taken.
What are the possible results of genetic testing for known familial MUTYH mutations?

1. You have not inherited the family MUTYH mutations

   Although an inherited tendency to bowel polyps and cancer is present in your family you have not inherited it. Your own risks of developing bowel cancer are not increased but will be the same as anyone else in the general population. We recommend that you remain symptom aware and report any concerns promptly to your GP.

   As you do not have the MAP mutations you cannot pass them on to your children.

2. You have inherited one of the MUTYH mutations

   You are a carrier of MAP. You are believed to have a small to moderately increased risk of developing bowel cancer. We would recommend you have a one-off colonoscopy screen of your bowel at the age of 55 years.

   There is a 50:50 (1 in 2) chance that you will pass it on to your children and, like you, they will be carriers of MAP. However, they will only be affected with MAP if your partner is also carrier. The population carrier risk for MAP is 1 in 50. You can discuss with your genetic counsellor whether it is appropriate to test your partner to see if s/he is also a carrier.

3. You have inherited both of the MUTYH mutations

   You have inherited MAP and will require regular screening.

   Your children will definitely be carriers of the condition. However, they will only be affected by MAP if your partner is also a carrier of MAP. You can discuss with your genetic counsellor whether it is appropriate to test your partner to see if s/he is also a carrier.

Management of individuals with MAP

People who have MAP can begin to develop polyps in their late twenties. A minimum of two yearly screening of the large bowel should start from around 25 years old.

   Sometimes if an individual with MAP has a large number of polyps, it may be recommended that they have part or most of their large bowel removed. Your surgeon will discuss whether surgery is appropriate in your particular situation. You will still need regular screening of your remaining large bowel.

   Some people with MAP can also develop polyps in their stomach and duodenum, so we also recommend screening via upper endoscopy a minimum of every 3 years from age 25.

Do lifestyle and diet make any difference to the development of polyps and bowel cancer in MAP?

Currently there is no definitive scientific evidence to suggest that there are specific lifestyle or dietary factors that reduce or increase the incidence of bowel polyps/bowel cancer in MAP.

   However, there is evidence to suggest that a healthy lifestyle including not smoking, limiting alcohol consumption, maintaining a healthy weight and being physically active can reduce the overall risk of developing cancer.

Symptoms

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 GP aware of your family history and you may wish to take this leaflet with you.