NHS
University Hospital Southampton
NHS Foundation Trust

MUTYH associated polyposis (MAP)

Information for patients

We have written this booklet to provide information about a condition called MUTYH associated polyposis (MAP). This condition is related to an increased risk of bowel polyps and bowel cancer. If you have any questions or would like more information, please contact a member of our genetics team using the contact details on page 6.

What is MUTYH associated polyposis (MAP)?

MUTYH associated polyposis (MAP) is an inherited condition (passed down from parent to child). It is associated with an increased risk of developing multiple bowel polyps and bowel cancer.

Bowel polyps are small growths on the inner lining of the large intestine (colon) or rectum (back passage). There are many types of polyps. Adenomas are the type of polyp commonly associated with MAP. If we do not remove adenomas, there is a chance that they may become cancerous if left to grow.

It is normal for an adult to develop some bowel polyps as they get older. However, it is unusual to have lots of bowel polyps. If a person has multiple bowel polyps, it is known as 'polyposis'.

MAP can increase the likelihood of a person developing lots of bowel polyps. This can lead to an increased risk of bowel cancer. People with MAP can have extra screening to look for bowel polyps and remove them.

What causes MAP?

Although MAP is an inherited condition, a person may be the first in their family to develop the condition.

Our bodies contain thousands of coded messages called genes. Genes send instructions to our body about how to function (for example, what colour to make our eyes or how tall we will grow). Some genes help to protect us from developing cancer.

MAP is caused by genetic variants (like spelling mistakes) in the MUTYH gene. The MUTYH gene has a key role in repairing damage to our bodies that occurs during normal daily life. Genetic variants in the MUTYH gene stop it from working properly. This can make someone more susceptible to developing bowel polyps and bowel cancer.

How is MAP inherited?

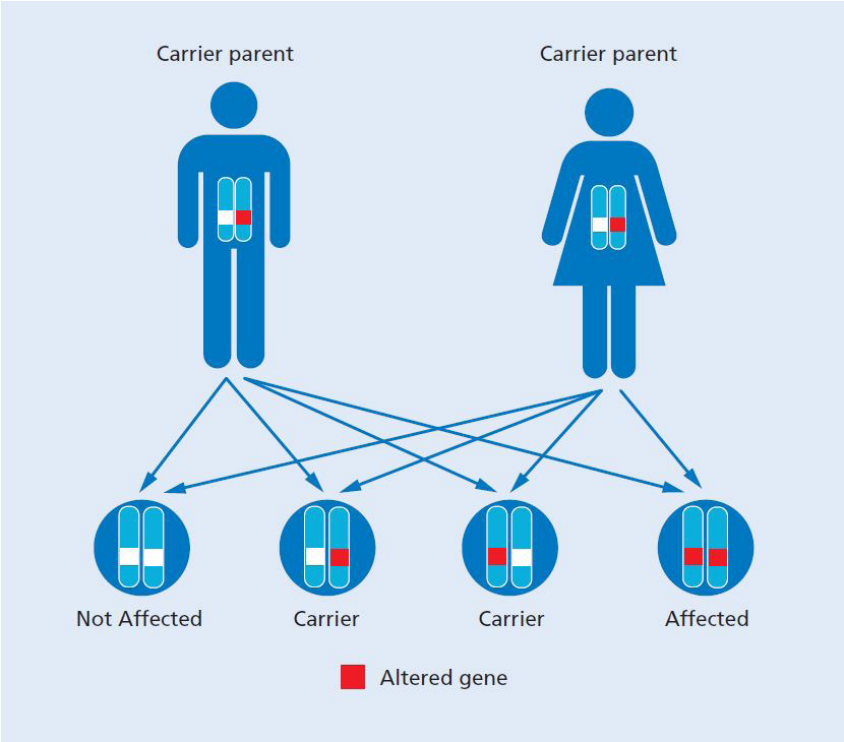
We all have two copies of each of our genes as we inherit one copy from our mother and one from our father.

If someone has a genetic variant in **both** copies of the MUTYH gene, that person has MAP and may develop bowel polyps. They will also have an increased risk of developing bowel cancer.

People who have a genetic variant in **one** copy of the MUTYH gene are known as carriers of MAP. Carriers of MAP are typically healthy with no signs or symptoms of the condition. This is because they still have one working copy of the MUTYH gene to compensate. 1 in 70 people in the UK population are a carrier of MAP.

When we have children, we pass on just one copy of each gene. The other copy comes from the other parent. If both parents are carriers of MAP, each child has a 1 in 4 (or 25%) chance of having MAP (from inheriting two MUTYH gene variants).

We call this autosomal recessive inheritance. We have shown this in the diagram on the next page:



Genetic testing for MAP

We can look for genetic variants in the MUTYH gene which can cause MAP by testing DNA extracted (taken) from a blood sample.

Please note that we offer genetic testing to the person in the family who has a suspected diagnosis of MAP first before offering testing to any other family members.

Why am I being offered genetic testing?

We may offer you a genetic test for MAP if you:

- have multiple polyps in your bowel
- have bowel cancer and you have a family history of bowel cancer or multiple bowel polyps
- develop bowel cancer before the age of 40

We will offer you an appointment with a genetic counsellor or doctor to help you decide if genetic testing is right for you.

During this appointment, we will discuss the:
- risks and benefits of having a genetic test
- potential outcomes of the genetic test and what they mean
- risk of you and your partner passing on MAP to your children

This appointment is a good opportunity for you to ask any questions you may have.

What happens if I have MAP?

If your genetic test result shows that you have two MUTYH gene variants, this means that you have MAP.

As MAP is associated with an increased risk of developing bowel polyps and bowel cancer, we recommend that people with MAP have extra screening. This includes:

- **A colonoscopy every year from the age of 18.** A colonoscopy is a procedure where a long, flexible tube with a camera attached (colonoscope) is passed through the anus into the large bowel.

- **Regular gastroscopies from the age of 35.** A gastroscopy is a procedure where a tube with a camera attached (gastroscope) is passed down the throat into the stomach and small intestine.

Screening is important for detecting early signs of cancer and bowel polyps. If bowel polyps are left, they have the potential to develop into a cancer over time.

If any bowel polyps are present, the endoscopist (a healthcare professional who performs endoscopy procedures, such as a colonoscopy or gastroscopy) will usually try to remove them during the procedure. These polyps will then be sent to the laboratory to check for any signs of cancer.

If we detect cancer at an early stage, treatment is more likely to be successful.

Please note that not all individuals with MAP will develop bowel cancer.

Can other family members have genetic testing?

If your result shows that you have two MUTYH gene variants, genetic testing may be available to other family members. If this is the case, your family members may wish to ask their GP for a referral to their local genetics service for advice about genetic testing for MAP.

Are there any alternatives to genetic testing?

You can choose not to have genetic testing. However, you should still have regular bowel screening as recommended by your healthcare team.

The team involved in your care

Consultant: .....

Telephone: .....

Genetic counsellor: .....

Telephone: .....

Contact us

If you have any questions or would like further advice about MAP, please contact us at:

- **Wessex Clinical Genetics Service**
  Princess Anne Hospital
  Coxford Road
  Southampton
  SO16 5YA

Telephone: **023 8120 6170** (Monday to Friday, 8am to 4pm)
Website: **www.uhs.nhs.uk/genetics**

Notes

This booklet was written by:

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If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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