

Familial Adenomatous Polyposis (FAP)

Information Guide

What is FAP?

FAP stands for Familial Adenomatous Polyposis. Individuals with FAP have an increased chance of developing cancer. People with FAP develop multiple polyps (small growths) in their bowel. The polyps usually begin to appear in adolescence, but the age at which they develop can be variable. The polyps themselves are not dangerous, but if left untreated one or more will turn into cancer. The condition affects both men and women.

What causes FAP?

FAP is a genetic condition caused by a change in a gene known as APC. Genes come in pairs because we get one copy from each parent. In FAP, one copy of the APC gene has a fault in it and the other copy is normal. FAP is called a dominant condition because the faulty copy of the gene is dominant over the normal copy.

The inheritance of FAP

FAP is usually passed from parent to child (of either sex). Some people with FAP are the first person diagnosed with the condition in their family. This may be because the fault in the gene occurred for the first time in the sperm or egg that made them, or it may be that FAP was not recognised in previous generations of the family. Each time an individual with FAP has a child, the child has a 50% chance of having FAP and a 50% chance of being unaffected by FAP.

Genetic testing for FAP

We can look for the exact APC gene fault which has caused FAP if we have a blood sample from a person who has the condition. In different families, there are different mistakes in the gene. We are able to identify the mistakes in most (80%) of people with a diagnosis of FAP.

Family members of a person with FAP

Relatives of a person with FAP often want to know if they will develop the condition. If the exact gene fault is known in a family, then we can offer a blood test to relatives to see if they have inherited FAP. The test is available from 10 years of age because polyps usually start growing around puberty.

Alternatively (or if the gene fault has not been identified) a camera examination of the bowel can be carried out to look for bowel polyps. The frequency of screening depends on whether polyps are found in the bowel.

Management and treatment for FAP

People with FAP need to have a camera examination of the bowel every 1-3 years to monitor the number and size of polyps. Initially, polyps can be removed during this examination, but as their number increases this becomes too difficult.

Eventually, planned surgery to remove the large bowel is required to prevent cancer. Sometimes this means using a temporary bag (stoma), but this is rarely permanent. Normal bowel function is usually regained after surgery.

Polyps can also grow in the stomach and the duodenum (the exit of the stomach). These polyps are much less likely to turn into cancer. The polyps need to be checked for every 3-5 years from the age of 30. This is done by a camera examination down the throat.

Other features of FAP

There are a few other features that are associated with FAP, such as extra spots of pigment at the back of the eye and bony lumps on the jaw, but these usually go unnoticed and do not cause any problems.

Attenuated FAP

Some families with FAP have fewer polyps and these develop later in life. This is called attenuated FAP. It is inherited in the same way as classical FAP but means less frequent screening is necessary, and it can often start at a slightly older age.

Suggestions, concerns and complaints

If you wish to make a comment, have a concern or want to complain, it is best in the first instance to speak to the manager of the ward or department involved.

The Trust has a Patient Advice and Liaison Service (PALS) who can be contacted on (0161) 276 8686 and via e-mail: pals@cmft.co.uk. They will help you if you have a concern, want advice or wish to make a comment or complaint.

Information leaflets about the service are readily available throughout the Trust. Please ask any member of staff for a copy.

For more information:

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

Genetic Medicine

Sixth Floor
St Mary's Hospital
Oxford Road
Manchester
M13 9WL

Telephone: 0161 276 6506 (*Reception*)

Facsimile: 0161 276 6145

www.mangen.co.uk

Department staffed Monday – Friday 8.30am to 5.00pm

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio, British Sign Language video/DVD) or in another language.

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The NHS has the responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service

Do you have difficulty speaking or understanding English ?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

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ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

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