



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

Information leaflet for
patients and families

FAP for children



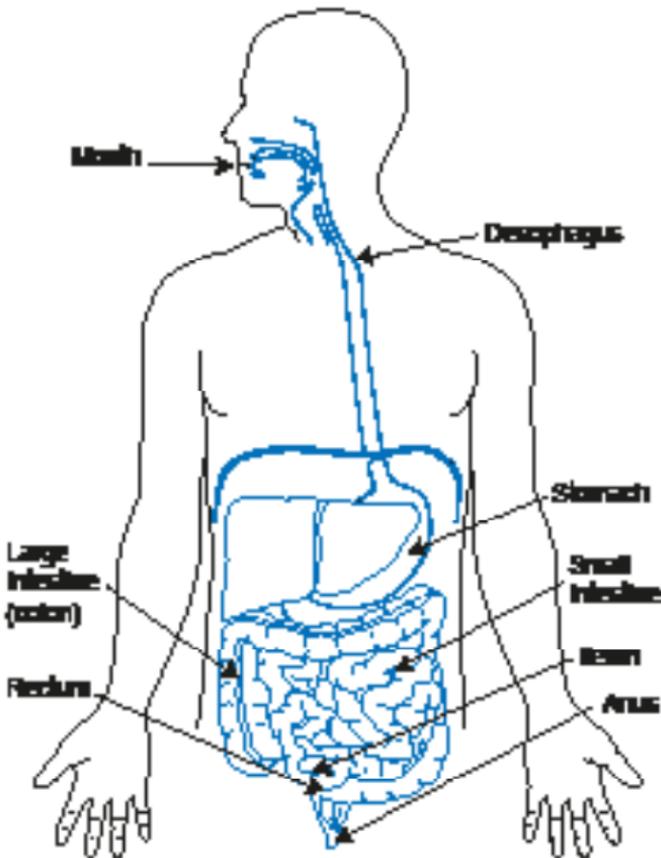
By your side

What is FAP?

FAP stands for Familial Adenomatous Polyposis. FAP affects several parts of the body, but mostly the digestive system.

This system breaks down food to give you energy and makes waste. When you eat, the food that you swallow goes down a tube called the oesophagus (sometimes spelt esophagus) and into your stomach.

It goes from your stomach to your small intestine, and then enters your large bowel (this is also known as the large intestine or colon). The job of the large bowel is to remove extra water or fluid from the waste. The waste from your body then moves from the large bowel to the rectum, and is pushed out when you have a bowel movement (doing a poo).

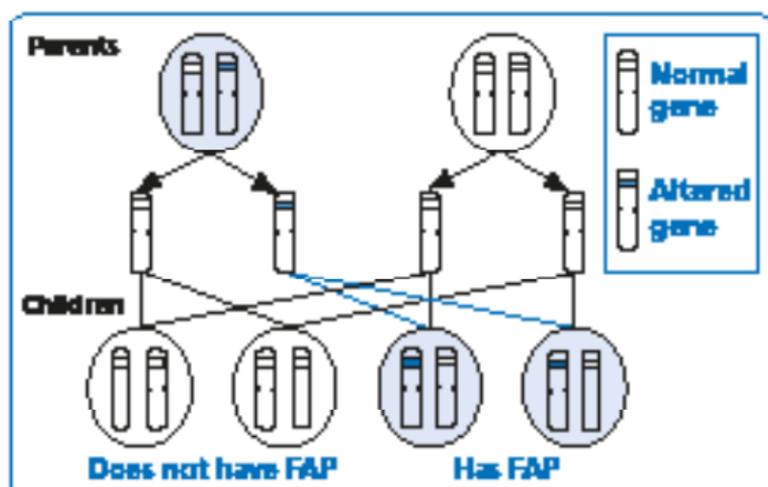


If someone has FAP, they get small growths, called polyps, in their digestive system, especially the large bowel and rectum. These usually start to grow when someone is about 10 or 11 years old. You cannot feel polyps grow and they do not make you ill, but they need to be removed as they can turn into cancer. Cancer is when cells in the body grow out of control, and make you ill. You may get polyps growing in other parts of the body but these do not usually turn into cancer.

Will I get FAP?

FAP runs in families. This is because it is in our genes. Genes are like a recipe for making a person – they tell the body how to work. We get half our genes from our mum and the other half from our dad.

A change in one of our genes, called APC, stops it from working properly and causes FAP. If one of your parents has FAP, there is a 50% chance, or 1 chance in 2, of you getting FAP. This is the same as the chance of a coin landing on heads when you toss it. This chance is the same for every child in the family.



How do I know if I have FAP?

If you already have polyps, then you know you have FAP.

Your family may have FAP if:

- Several family members have had bowel cancer or polyps
- One of your relatives has had lots of polyps
- A relative has had bowel cancer at a young age with polyps

To see if you have FAP you may be able to have a genetic test. This is usually a blood test and will tell you if you have FAP or not. Someone will talk to you about this before they take the blood and the result will be ready in about 3 weeks. If you do not have FAP you do not need to have anything else done.

Someone will talk to you about this before they take the blood, and then the results will take a few weeks. If you do not have FAP, you do not need to have anything else done.

What if I have FAP?

If you have FAP, you will usually have to be checked for polyps once a year. Before the check you will have to stop eating for a while and take some medicine to clear out the large bowel. Doctors check for polyps by using a thin flexible tube with a light on the end called a colonoscope.

The scope goes from your bottom into your large bowel. It has a tiny camera on the end that shows the inside of your large bowel. If the doctor finds any polyps, they may take them out if there are only one or two or if they are big. This does not usually hurt – you can't even feel it.

It is also a good idea to tell someone if you notice anything different when you go to the toilet, such as diarrhoea, constipation, blood in your poo, if you have pain in your stomach or if you think you are

losing weight. However, you will need colonoscopies even if you don't notice anything unusual.

What if I need an operation?

Most people who have FAP start to get polyps sometime between the ages of 10 and 18. At first, there may be just a few polyps. After a while, there are too many polyps to remove. When this happens you will need to talk to your doctors about the best time to have an operation to remove your large bowel. If left untreated for a long time some polyps will grow into cancer. If you have your large bowel removed, you will have a much lower chance of getting cancer. There are different types of operations. Your doctor and your parents can tell you more about the kind of operation you might have, when you will need it and what you can expect during and after the operation. Don't worry, a person can live a long, happy, healthy life without a large bowel.

Where can I get further information?

Some information can be found on the following websites. You may wish to wait until after your appointment so that we can direct you to information most appropriate to you.

www.macmillan.org.uk/Home.aspx
www.cancerresearchuk.org

This leaflet is based, with permission, on a leaflet from the Clinical Genetics Department at Guy's Hospital.

If you need more advice about any aspect of FAP for children 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

Author: Tricia Heaton
Author Title: Genetic Counsellor
Reviewed and updated: June 2017
Next review: June 2020
Ref No: CG15/FAPc

