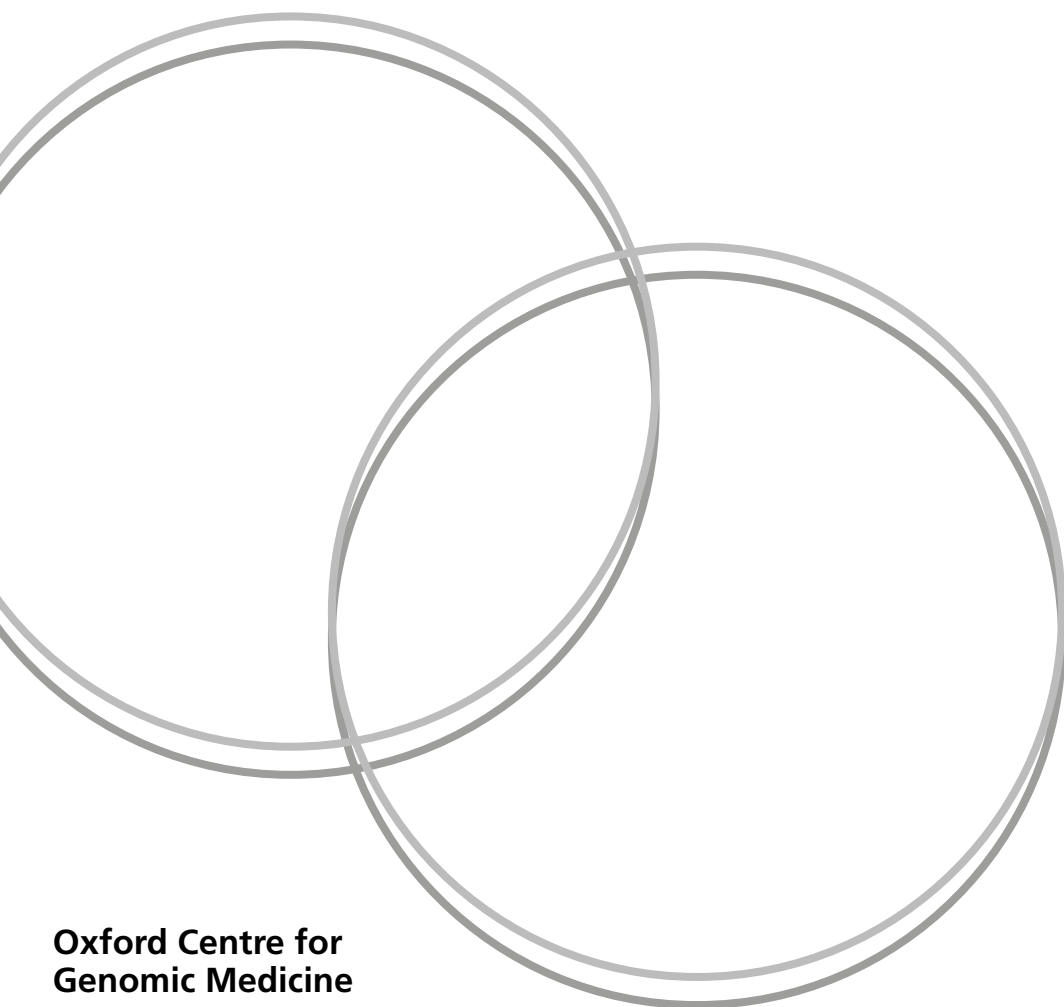




**Oxford University Hospitals**  
NHS Foundation Trust

# **FAP for children**



**Oxford Centre for  
Genomic Medicine**

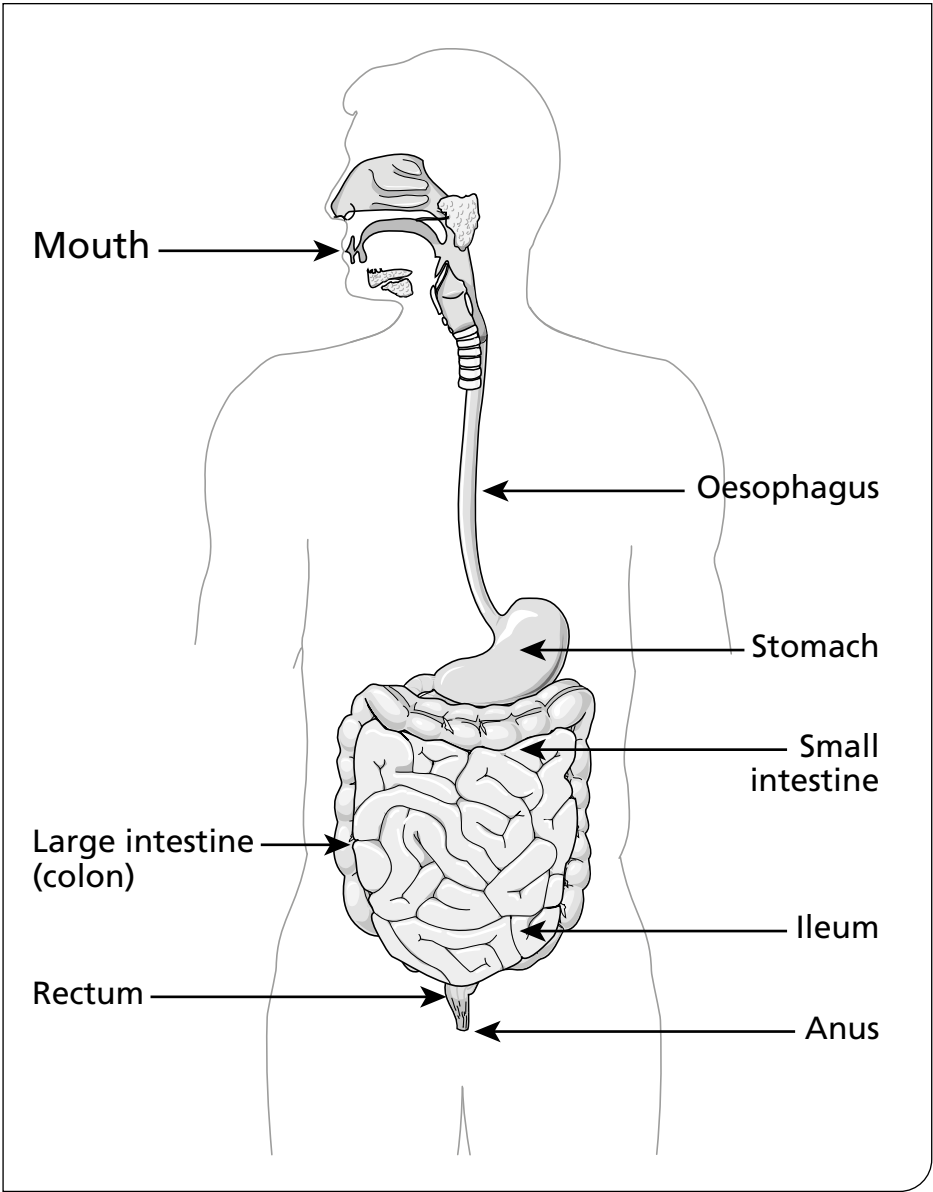
## What is FAP?

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 bowel (firstly into the small intestine and then into your 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).

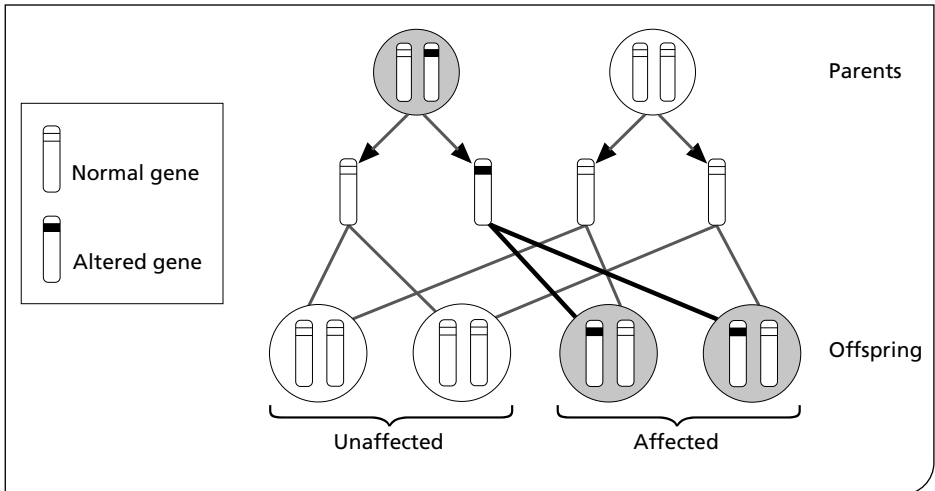
If someone has FAP, they get small growths, called polyps, in their digestive system, especially the large bowel and rectum. These usually start to grow when someone is about 10 or 11 years old. You cannot feel polyps grow and they do not make you ill, but they need to be removed as they can turn into cancer (when cells in the body grow out of control and make you ill). You can also get polyps growing in other parts of the body but these do not usually cause 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, like 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 already know you have FAP. If you don't have polyps yet, you may be able to have a genetic blood test to find out if you have FAP. This can be done when the alteration in the gene which has caused FAP in your family is known. If the gene alteration has not been found in a relative with FAP you cannot have a blood test to show if you have FAP. The genetic test is usually a blood test and will tell you whether or not you have FAP. Someone will talk to you about this before they take the blood.

The results will take a few weeks and if they show 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. The test works best when your bowel is completely empty, so before the check you will have to stop eating for a short while and drink some strong medicine. This will make you go to the toilet several times.

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 usually does not 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 or 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 may be 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 about cancer 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.

Website: <http://www.macmillan.org.uk/>

Website: <http://www.cancerresearchuk.org/>

Website: <http://www.fapgene.org.uk>

## **If you need more advice please contact:**

### **Oxford Cancer Genetic Service**

Oxford Centre for Genomic Medicine  
ACE building (Room 33G16)  
Nuffield Orthopaedic Centre  
Oxford University Hospitals NHS Foundation Trust  
Windmill Road  
Headington  
Oxford OX3 7HE

Tel: **01865 226 034**

Email: [orh-tr.churchill-clinicalgenetics@nhs.net](mailto:orh-tr.churchill-clinicalgenetics@nhs.net)

Website: <http://www.ouh.nhs.uk/clinical-genetics>

## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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This leaflet is based, with permission, on a leaflet produced by the West Midlands Regional Genetic Service.

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