



Familial Adenomatous Polyposis (FAP)

This factsheet gives information on a bowel condition called familial adenomatous polyposis (FAP) that occurs in some families. It describes what familial adenomatous polyposis is, how it is passed on and what happens if you have this condition. If you have any other queries or concerns about it, please contact the **National Cancer Helpline 1800 200 700** or speak to your GP.

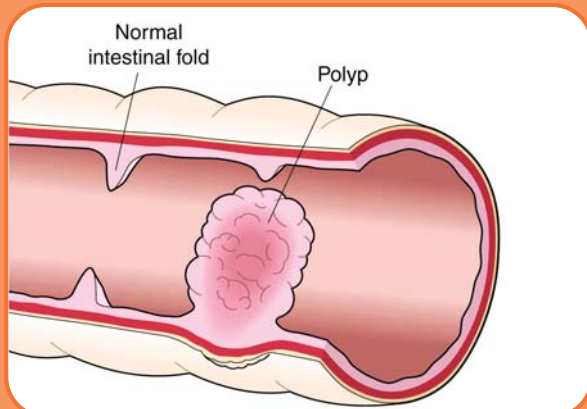
What is familial adenomatous polyposis?

Familial adenomatous polyposis (FAP) is a genetic condition where hundreds or thousands of polyps develop in the large bowel (colon). These polyps or adenomas start to grow during teenage years. If left untreated, they can develop into cancer. FAP is passed on between families (inherited) and it is very rare.

There is also a more rare form of FAP called attenuated FAP. This condition is like FAP but you get far less polyps in the bowel. Also, the polyps usually develop into cancer at an older age than those with regular FAP.

What is a polyp?

A polyp is an abnormal growth of tissue in the lining of your bowel (colon). They can often vary in size. Colon polyps are very common and most are harmless. But if left untreated, they can lead to cancer.



How is FAP inherited?

Genes are found in all the cells that make up your body. They hold your genetic material (DNA) and are responsible for many things like the colour of your eyes and how tall you are. They also contain information that tells your body how to work and grow. Genes are passed on from your parents to you, which means you inherit them.

Sometimes a gene develops a fault or mutation. If you inherit a faulty gene at birth, it means that the cells in your body are more likely to get changes that can lead to cancer. FAP is caused by a mutation or change in the gene called adenomatous polyposis coli (APC). This faulty gene leads to the uncontrolled growth of polyps, which if left untreated will develop into a cancer.

A person with FAP has a 1 in 2 chance (50%) of passing the condition on to their children. Some people with FAP do not inherit it from their parents, however. In their case, they have a new change in the gene and are the first in their family to have the condition. They can then pass the gene on to their children.

How can I find out if I have FAP?

There are two ways to find out if you have FAP: bowel screening and genetic testing.

Bowel screening can look for polyps, while a genetic test can see if there is a change in a gene. However, FAP may be diagnosed due to a family member having the condition or because you are found to have many polyps in your bowel.

What is genetic testing?

Genetic testing involves taking a blood sample. This is then sent to a special laboratory to try and find the particular fault in the gene. In Ireland, genetic testing is done at the National Centre for Medical Genetics at Our Lady's Children's Hospital, Crumlin, Dublin. It may be many weeks before you get the results of the tests.

If you do need genetic testing, you will be given information and counselling before the test as well as after getting the results.

Who can be tested?

There are two stages to genetic testing within a family. First, a family member with FAP gives their consent to have genetic testing to see if the faulty gene can be identified.

If a fault is found in that family member, then genetic screening can be offered to other members of the family. It is up to each family member to decide if they wish to be tested or not.

What happens if a family member has FAP?

If either of your parents has FAP, you have a 1 in 2 chance (50%) of inheriting the gene. In this case, you will be invited to go for genetic screening. If you inherit a gene, it increases your risk of getting bowel cancer. You will therefore be advised to go for regular bowel screening.

What is bowel screening?

If you are known to carry the FAP gene, bowel screening will start at a young age, usually between 10 and 14 years of age. Bowel screening involves a test called a colonoscopy. This is where a flexible tube with a camera on top is used to check your bowel for polyps. If a polyp is found, your doctor can take a small sample of the tissue to have it looked at in the laboratory. If there are lots of polyps in the bowel or if a polyp looks like a cancer, your doctor may advise you to have an operation.

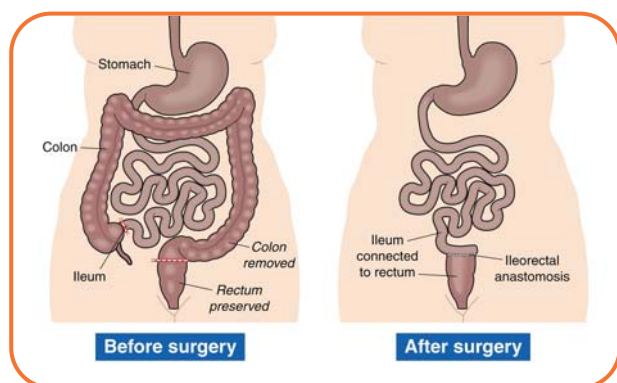
How is FAP treated?

If you have FAP, you will be advised to have a colonoscopy every year from the age of 10–14 years. If you have many polyps that would be hard to remove one by one, you may be advised to have one of three operations. These are:

1. Colectomy with ileorectal anastomosis (IRA)
2. Restorative proctocolectomy
3. Proctocolectomy and ileostomy

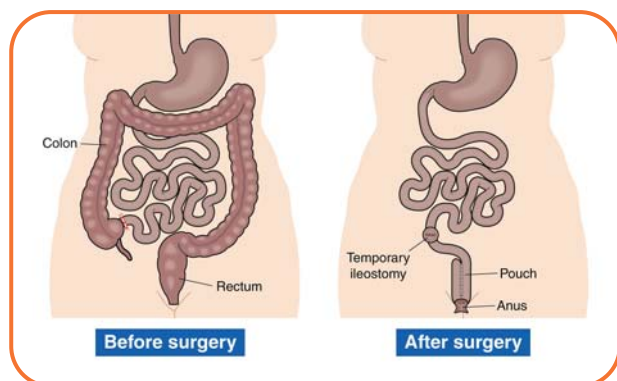
Colectomy with ileorectal anastomosis

In this operation the large bowel (colon) is removed and the small bowel (ileum) is joined to the rectum (back passage). The back passage will still have to be screened every year as polyps can grow here. Many young patients prefer to have this operation. However the rectum will need to be removed at a later date.



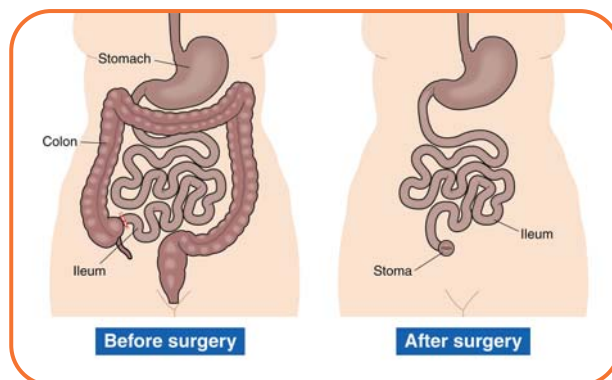
Restorative proctocolectomy

In this operation the large bowel and the rectum are removed. A pouch is made from the small intestine (ileum) and is used to replace the rectum. This is then joined to the anus.



Proctocolectomy and ileostomy

In this operation the large bowel, back passage and anus are removed. The small bowel (ileum) is then joined to the surface of the abdomen (stomach). This is called a stoma or ileostomy. Bowel motions can then pass from the bowel into a disposable bag attached to the stoma on your skin.



The type of surgery that is recommended by your surgeon will depend on your age, your wishes and your understanding of each operation.

What happens if I do not inherit the gene?

If you do not inherit an abnormal gene, you do not need any special screening. This is because your risk of getting cancer is the same as the rest of the population. But you should continue to be aware of any changes in your bowels. Tell your doctor if you have any new symptoms like bleeding from the back passage, weight loss or a change in bowel habit.

It is best not to smoke and only drink alcohol in moderation. You should also have a healthy diet, which is low in fat and sugars but high in fruit and vegetables. You should keep a healthy weight and take regular exercise to reduce your risk of getting cancer.

Support

Genetic testing and an inherited cancer can be hard for families to deal with. It is important to get support during this time. You may be able to get this help from other family members, from friends or from your genetic counsellor/nurse. You can also speak to a nurse on the **National Cancer Helpline 1800 200 700**.

Further information

If you are concerned about any aspect of your health or family history, you should contact your family doctor (GP). He or she will discuss your concerns and your family history and refer you to a specialist if needed.

For more information about FAP or about cancer in general, call the **National Cancer Helpline Freephone**

1800 200 700

(Monday–Thursday, 9am–7pm,
Friday 9am–5pm)
or email helpline@irishcancer.ie
for confidential advice from our
cancer nurse specialist.

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

Tel: **01 231 0500**
Fax: **01 231 0555**
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Useful organisations and websites

The Polyposis Registry (UK)

St Mark's Hospital Foundation
Watford Road, Harrow
Middlesex, HA1 3UI, UK

Tel: +44 (0) 208 235 4270
Email: info@polyposisregistry.org.uk
Website: www.polyposisregistry.org.uk

The Johns Hopkins Guide for Patients and Families: APC I1307K Gene Mutation

Website: www.macgn.org/cc_apc1.html

American Cancer Society

Website: www.cancer.org

Citizens Information Board

7th Floor, Hume House
Ballsbridge, Dublin 4

Tel: 01 605 9000
Email: information@ciboard.ie
Website: www.citizensinformation.ie

The National Centre for Medical Genetics

Our Lady's Children's Hospital
Crumlin, Dublin 12

Tel: 01 409 6793
Website: www.genetics.ie

Published by the Irish Cancer Society.

© Irish Cancer Society, 2009

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

National Cancer Helpline: **1800 200 700**