



Familial adenomatous polyposis (FAP)

An inherited condition that causes many polyps in the bowel

PE-GIC-32

FAP is an inherited condition in which hundreds to thousands of polyps grow in the large bowel, usually starting in the teenage years. Without treatment, bowel cancer is almost certain. Early screening, well-timed surgery and lifelong follow-up allow people with FAP to lead full lives.

What is it?

FAP is caused by a change (variant) in the APC gene, which normally controls cell growth in the bowel lining. Polyps (adenomas) usually begin to appear in the teenage years and increase in number over time. Without surgery, one or more of them will almost certainly become cancer, often by early middle age.

FAP runs in families. Each child of an affected parent has a 1 in 2 chance of inheriting it. In about a quarter of people there is no family history, because the gene change has arisen for the first time in them.

Symptoms

Polyps often cause no symptoms until they are numerous, which is why screening starts early. Possible symptoms:

- Blood in the stool
- Diarrhoea or a change in bowel habit
- Abdominal pain
- Tiredness from anaemia

Screening in families

- Children of an affected parent are offered genetic testing for the known family gene change, usually around age 12 to 14, with genetic counselling for the family
- Those who carry the gene change start bowel examinations (colonoscopy or flexible sigmoidoscopy) from about age 12 to 14, repeated every 1 to 3 years depending on what is found
- Children who do not carry the gene change do not need extra checks
- A child with bowel symptoms such as bleeding should be assessed earlier

Surgery

Removing the large bowel (colectomy) is the main way to prevent cancer. It is usually done in the late teens or twenties, timed by the number and size of polyps and planned around education, work and family. The main options are:

- Colectomy with ileorectal anastomosis: the colon is removed and the small bowel is joined to the rectum. The rectum still needs regular checks, because polyps can grow there
- Proctocolectomy with an ileal pouch: the colon and rectum are removed, and a pouch made from the small bowel is joined to the anus. The pouch also needs regular checks
- Occasionally, a permanent stoma

Your surgeon will explain which option suits you, its effect on bowel function, and, for women, any effects on fertility and pregnancy.

Lifelong follow-up

After bowel surgery, other parts of the body still need checks:

- Duodenum (the first part of the small bowel): most people with FAP develop polyps here. Regular gastroscopy, usually from about age 25, checks the duodenum and the opening of the bile duct, at intervals based on the polyps found. Duodenal cancer is now one of the main cancer risks after colectomy
- Stomach: polyps are common and usually harmless, and are checked at the same gastroscopy
- Thyroid: an ultrasound may be offered, because thyroid cancer is more common in FAP

- Desmoid tumours: firm growths in the abdominal wall or inside the abdomen, often after surgery. They do not spread like cancer but can grow and press on nearby organs; a specialist team manages them, sometimes by monitoring alone

Milder and related forms

- Attenuated FAP: also due to APC changes, but with fewer polyps (often fewer than 100) appearing later. Screening starts later, and some people can be managed with colonoscopy and polyp removal rather than early surgery
- MUTYH-associated polyposis (MAP): caused by a different gene, and usually leads to tens to hundreds of polyps in adulthood. A person is affected only if they inherit a faulty copy from both parents, so each brother or sister has a 1 in 4 chance. This is more likely when parents are related to each other. Children are usually not affected unless the other parent is also a carrier
- Genetic counselling is recommended for everyone with FAP or MAP, and for their families

Get urgent medical care if you have

- Heavy rectal bleeding or passing clots
- Black, tarry stools or feeling faint
- Severe abdominal pain, vomiting or abdominal swelling (possible blockage, including from a desmoid)
- Yellowing of the skin or eyes
- A new or growing lump in the abdomen or abdominal wall

Common questions

Can FAP be treated without surgery?

In classical FAP, no medicine or diet can replace surgery. Medicines to reduce polyps have been studied, but they are not a substitute. Some people with milder forms can be managed with regular colonoscopy.

Can I have children?

Yes. Most people with FAP can have children. Genetic counselling explains the chance of passing it on and the options available, and can be done in confidence before marriage or pregnancy.

Why is the duodenum still checked after colectomy?

Because polyps there can also become cancer. Regular gastroscopy allows them to be treated early.

What if our family gene change is not known?

If genetic testing cannot find the family gene change, at-risk relatives are usually offered regular bowel examinations instead, up to an age agreed with the specialist team.

This leaflet is general information and does not replace advice from your own doctor. Version 1.0, October 2026. Next review October 2028.

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