



Crohn's disease

Information for people with inflammatory bowel disease

PE-IBD-01

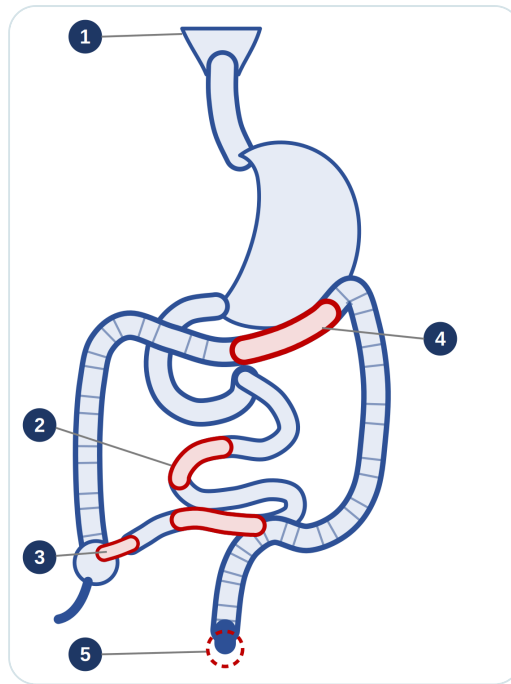
Version 1.0 · Last reviewed October 2026 · Next review October 2028

This sheet explains what Crohn's disease is, how it is monitored, how it is treated, and when to contact your doctor. Please bring it with you to your clinic appointments.

What Crohn's disease is

Crohn's disease is a long-term condition in which the immune system attacks the lining of the gut and causes inflammation and ulcers. It can affect any part of the digestive tract, from the mouth to the anus, but the last part of the small bowel (the terminal ileum) and the colon are the commonest sites. The inflammation comes in patches, with healthy gut in between, and it can involve all layers of the bowel wall. This is why Crohn's can cause narrowing (a stricture), a collection of pus (an abscess), or an abnormal channel between the bowel and another surface (a fistula).

Crohn's disease is not caused by anything you did or ate, and it is not infectious. A mix of inherited genes, the bacteria in the gut and environmental factors is thought to cause it. It cannot be cured, but for most people it can be well controlled with treatment.



1 Any part, from mouth to anus 2 Patches of inflammation with healthy gut in between 3 Terminal ileum – the commonest site 4 Colon 5 Around the anus (perianal disease)

Your type of Crohn's disease

We record where your disease is and how it behaves, using the Montreal classification. Location: L1 the last part of the small bowel, L2 the colon, L3 both; L4 is added if the upper gut is also involved. Behaviour: B1 inflammation only, B2 narrowing, B3 fistulising. A small "p" is added if you also have disease around the anus. Your doctor will tell you your type, and it may change over time.

Symptoms

- Diarrhoea, sometimes with blood or mucus, and needing to rush to the toilet
- Cramping abdominal pain, often in the lower right side
- Tiredness, loss of appetite and weight loss
- Mouth ulcers; pain, swelling or discharge around the anus
- Problems outside the gut – joints, eyes, skin, liver and anaemia. Around one in three people with Crohn's develop at least one joint, skin or eye problem of this kind.

Tests we use

Colonoscopy with biopsies is the main test for diagnosis and for checking how well treatment is working. MR enterography looks at the small bowel and uses no X-ray radiation. Intestinal ultrasound is quick, painless and can be repeated in clinic. Capsule endoscopy may be used for the small bowel. Blood tests and a stool test for faecal calprotectin are used between endoscopies – see sheet [PE-IBD-03](#).

Treatment

A flare is usually settled with steroids (prednisolone or budesonide), and a separate medicine is then used to keep the disease settled. Mesalazine and other 5-ASA medicines do not work in Crohn's disease and are not recommended. Maintenance options are azathioprine or mercaptopurine, methotrexate, and biologic medicines including infliximab, adalimumab, ustekinumab, vedolizumab and risankizumab. Each of these has its own information sheet. Exclusive liquid nutrition is an alternative to steroids in some people.

Modern practice is to start effective treatment early rather than waiting for the disease to progress. In a large UK trial of newly diagnosed patients, 79 per cent of those given early combined treatment were in remission without steroids or surgery at one year, compared with 15 per cent treated step by step.

The aim of treatment is not only that you feel better, but that we can no longer measure any inflammation – symptoms and inflammation do not always match. We usually reassess with calprotectin, and often with endoscopy or a scan, about six to nine months after starting a new treatment.

Surgery

Around one in five people with Crohn's disease need major surgery in the first five years after diagnosis. The commonest operations are removing a short diseased segment (a resection), widening a stricture without removing bowel (a strictureplasty), draining an abscess or placing a seton for a fistula, and occasionally forming a stoma. Surgery treats the complication but does not cure Crohn's, so medicine is usually continued or started afterwards to reduce the chance of it returning.

Smoking

Smoking makes Crohn's disease worse. Smokers have more flares, are more likely to need surgery, and are more likely to need a second operation. When people stop smoking, these risks fall back towards those of a non-smoker, so it is never too late to stop. You are about three times more likely to succeed with specialist support than on your own; please ask your doctor to refer you.

Bowel cancer and surveillance

If Crohn's disease affects the colon, the risk of bowel cancer is higher than in the general population – roughly double, and considerably more if the colitis is extensive or began at a young age. Because of this we offer regular surveillance colonoscopy starting eight years after your symptoms began, at an interval that depends on your own risk. Surveillance starts from the time of diagnosis if you also have primary sclerosing cholangitis. Disease limited to the last part of the small bowel does not need surveillance.

When to contact your doctor

Symptom	What to do
Loose stools with blood or mucus for more than three days	Contact the IBD clinic
New or worsening abdominal pain, or waking at night to open your bowels	Contact the IBD clinic
Fever above 38°C while on medicine that affects the immune system	Same day – contact your doctor or attend the Emergency Department
Severe abdominal pain with vomiting, and no wind or stool passing	Emergency Department – this may be a blockage
Pain, swelling or discharge around the anus with fever	Emergency Department – this may be an abscess
Heavy bleeding from the back passage, or vomiting blood	Emergency Department

How to contact your doctor

Contact your doctor during working hours, using the numbers your clinic has given you, for anything that is not an emergency – a reaction to a medicine, symptoms that are changing, a question about your treatment, or a repeat prescription. Tell your doctor about any reaction to a medicine: that is what lets your doctor bring your appointment forward. Routine blood tests can be done and reviewed at your local health centre – you do not need to wait for us for that. If you are seriously unwell, go to the Emergency Department rather than waiting for a reply.

Living with Crohn's disease

There is no clear evidence that any particular food causes or cures Crohn's disease. Aim for a balanced diet and ask to see the dietitian if you are losing weight, avoiding many foods, or have a stricture. About half of people with Crohn's say the condition has affected their mental health at some point; tell your doctor if it is affecting yours, as help is available. If you are planning a pregnancy, tell your doctor before you conceive – we aim for the disease to be settled for three to six months first, and most Crohn's medicines are continued through pregnancy and breastfeeding. Vaccination advice is in sheet [PE-IBD-04](#).

Contact your doctor using the numbers your clinic has given you. If you are seriously unwell, or it is outside working hours, go to the Emergency Department rather than waiting for a reply. This sheet is general information and does not replace the advice of your own doctor. Version 1.0 · review date October 2028.

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ZAD Health, PE-IBD-01