



Tofacitinib

Information for people with inflammatory bowel disease

PE-IBD-16

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

Tofacitinib is a tablet that blocks JAK enzymes, which carry inflammation signals inside immune cells; it is taken by mouth, not given as an injection or a drip.

Why you are taking it

It is used for moderate to severe ulcerative colitis that has not responded to, or has stopped responding to, steroids, immunosuppressants or a biologic. It is not licensed for Crohn's disease, because it did not work well enough in Crohn's trials. It is a tablet, it works quickly and the body does not make antibodies against it; the trade-off is regular blood tests and close attention to infection and blood clots.

How to take it

The usual starting dose is 10 mg twice a day for eight weeks. If you have improved but not enough by then, we may continue 10 mg twice a day for another eight weeks; if there is no benefit by sixteen weeks we stop it. After that the usual dose is 5 mg twice a day for as long as it works. Some people need 10 mg twice a day to stay well; we use this higher dose only when the benefit outweighs the risks, and for the shortest time possible. Take the tablets morning and evening, with or without food; they can be crushed and taken with water if you find them hard to swallow. If you miss a dose, skip it and take the next one at the usual time – never take a double dose. Before the first dose we screen for tuberculosis with a chest X-ray and a blood test, check for hepatitis B and C, HIV and previous chickenpox, and recommend the shingles vaccine – see sheet [PE-IBD-18](#).

How long it takes to work

Tofacitinib works quickly. Many people notice less bleeding and urgency within one to two weeks, sometimes within days, and we assess the response at eight weeks. If

the response fades later, we can return to the higher dose for a time or change medicine.

Blood tests and monitoring

Before starting we check a full blood count, liver and kidney tests and cholesterol. We repeat the blood count and liver tests four to eight weeks after starting, check cholesterol at about eight weeks, and then test every three months – blood count, liver and kidney tests and a muscle enzyme called CK. If your cholesterol rises we may start a statin; the tablets can usually continue.

Side effects

Side effect	What it means and what to do
Infection, including chest, urine and skin infections	Common. Report fever or any infection early – see sheet PE-IBD-04 . We may pause the tablets until it has cleared.
Shingles – a painful blistering rash in a band on one side of the body – and cold sores	More common than with most other IBD medicines, especially on the higher dose. Contact your doctor the same day, as antiviral treatment works best if started early. The shingles vaccine lowers the risk – see sheet PE-IBD-18 .
Headache, cold-like symptoms, nausea, diarrhoea, rash	Common and usually mild.
Raised cholesterol	Common. It causes no symptoms and is found on blood tests. We treat it with a statin if needed.
Raised liver enzymes, or low white cell, lymphocyte or red cell counts	Found on blood tests, which is why we monitor them. We may lower or pause the dose.
Reactivation of tuberculosis or hepatitis B	Uncommon. The reason for screening. Report a persistent cough, night sweats or weight loss.

Blood clots in the legs or lungs

Uncommon, and more likely on 10 mg twice a day and in people with other risk factors. Chest pain, sudden breathlessness or a painful swollen leg need the Emergency Department.

Heart attack, stroke, and some cancers including lymphoma and skin cancer

Uncommon. In a large study of older people with rheumatoid arthritis and heart risk factors these were more common than with anti-TNF medicines – particularly lung cancer in people who smoked or had smoked – so we assess your own risk before starting. Protect your skin from the sun.

Important precautions

- Do not take the tablets if you have an active infection or a fever – contact your doctor first.
- Before starting, tell your doctor if you are 65 or over, smoke now or smoked for a long time in the past, have had a heart attack, stroke, blood clot or cancer, or have high blood pressure, diabetes or high cholesterol. Medicine regulators in Europe, the UK and the USA advise extra caution in these groups, and in Europe and the UK JAK inhibitors are used in them only when there is no suitable alternative. Tell your doctor too if you have liver or kidney disease, as the dose may need to change. Your team will discuss with you whether it is suitable.
- Tell your doctor before an operation, or if you will be confined to bed or unable to move about for a long time, as this raises the risk of a blood clot.
- No live vaccines (for example yellow fever, MMR, live chickenpox vaccine or BCG) during treatment; if one is needed it is given at least four weeks before you start. Non-live vaccines are recommended, and we strongly advise the shingles vaccine Shingrix – see sheets PE-IBD-04 and PE-IBD-18.
- Tell every doctor and pharmacist that you take tofacitinib. Some antibiotics and antifungals, such as clarithromycin, ketoconazole and fluconazole, raise its level and the dose must be lowered; rifampicin, used for tuberculosis, can stop it working. It is not combined with biologics, azathioprine, mercaptopurine, ciclosporin or tacrolimus.
- Do not stop the tablets yourself, even when you feel well. Tell your doctor if you have missed more than a day's doses or have run out.
- For a repeat prescription, message the clinic. If there is no reply after 48 hours send the message again, and if there is still no reply, come to the clinic.

Pregnancy and breastfeeding

Tofacitinib must not be taken in pregnancy. Women who could become pregnant should use effective contraception during treatment and for at least four weeks after the last dose; ask your doctor which method suits you, as the combined pill adds to the risk of clots. If you are planning a pregnancy, talk to your doctor first so they can change your medicine. If you become pregnant, phone your doctor the same day – do not wait for a reply to a message. In most cases we will stop tofacitinib and plan a medicine that is safe in pregnancy with you. Do not breastfeed while taking tofacitinib, or for at least 18 hours after the last dose.

Tell your doctor straight away if

- You have a fever, or any sign of infection.
- You develop a painful blistering rash, especially in a band on one side of the body.
- You have not had chickenpox and have been in contact with someone with chickenpox or shingles – contact your doctor within 24 hours.
- You have chest pain, sudden breathlessness, or a painful swollen leg – this may be a blood clot, so go to the Emergency Department.
- You have sudden weakness or numbness on one side, difficulty speaking, or sudden loss of vision – go to the Emergency Department.
- You have severe, constant tummy pain, especially with fever or vomiting.
- You have a cough lasting more than three weeks, night sweats or weight loss.
- Your symptoms return or get worse.

Tell your doctor so they know and can bring your appointment forward. But if you feel seriously unwell, go to the Emergency Department first – do not wait for a reply.

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. Brand names and preparations may differ – check the label on your own medicine. General safety advice is in sheet [PE-IBD-04](#). Version 1.0 · review date October 2028.

This leaflet is general information and does not replace advice from your own doctor.

