

Patient information

Drugs for Inflammatory Bowel Disease Tofacitinib

Digestive Diseases Care Group

What is Tofacitinib?

Tofacitinib is called a JAK inhibitor, it is a drug that works by suppressing the immune system – ideally back to a baseline level to prevent further inflammation, which will improve your symptoms of Ulcerative Colitis

What are the benefits of JAK inhibitors?

JAK inhibitors are useful for treating Ulcerative Colitis and keeping it under good control. They may be used when other treatments have failed.

Why have I been given Tofacitinib?

Tofacitinib is a drug used to treat patients with moderately to severely active Ulcerative Colitis (UC) who have had an inadequate response, lost response, or were intolerant to either conventional treatments such as azathioprine and steroids or a biologic agent.

Is Tofacitinib a biologic agent?

No, Tofacitinib is not a biologic agent.

How is Tofacitinib administered?

Tofacitinib is an oral medication which you take twice daily.

What dose of Tofacitinib do I have?

Your hospital doctor or specialist nurse will discuss the doses of the drug with you.

How long will it take to work?

It should work by approximately eight weeks but may work sooner in many people. Your doctor may continue the treatment to sixteen weeks if you have not noticed any improvement in your Ulcerative Colitis. If there is no benefit by week sixteen the drug will be discontinued.

Do I need any investigations before I start Tofacitinib?

Yes, prior to starting Tofacitinib you will require the following:

All patients prior to starting Tofacitinib therapy will require risk assessment for Pulmonary Embolism (PE/Blood clot within the lungs).

Chest X-ray to ensure that you do not have tuberculosis (TB), as drugs like Tofacitinib can, in some cases, re-activate old TB. We also complete a blood test to check for underlying TB, this test takes about ten days to get the result.

All patients should be brought up to date with all immunisations in agreement with current immunisation guidelines.

All patients should have bloods taken for:

Hepatitis screen/HIV/Varicella/Full blood count/liver function tests/lipid profile and inflammatory markers.

What are the side effects of Tofacitinib?

Recent safety trials for patients with rheumatoid arthritis found an increase occurrence of blood clots within the lungs (PE), if you fulfil any of the below criteria please notify your IBD specialist nurse.

- Use of HRT.
- Heart failure (no grade specified).
- Previous DVT or PE.
- Inherited coagulation disorder.
- Malignancy.

If you develop any of the following symptoms during treatment with Tofacitinib, we advise you to attend your local Emergency Department (A&E) urgently:

- Sudden Shortness of breath or difficulty breathing.
- Chest pain or pain in your back.
- Coughing up blood.
- Excessive Sweating.
- Clammy or bluish coloured skin.

Common side effects of Tofacitinib are:

- Upper respiratory tract infections.
- Headache.
- Diarrhoea.
- Cold symptoms, such as sore throat, runny or stuffy nose.

Rare side effects of Tofacitinib:

- **Cancers**

There has been rare reports of people developing cancer whilst on JAK inhibitors. These include cancers of the blood such as Lymphoma, and other cancers lung cancer, prostate cancer, skin cancer and pancreatic cancer. However, it is important to note that we have no evidence to say that Tofacitinib is associated with an excess risk of cancer.

- **Lung disease**

Lung disease has been reported in patients treated with Tofacitinib (some of which had a fatal outcome).

- **Gastrointestinal perforations**

Events of gastrointestinal perforations have been reported in clinical trials, although the role of Tofacitinib in these events are unknown.

- **Serious infections**

Most common serious infections are:

- Pneumonia.
- Cellulitis.
- Urinary tract infection.
- Diverticulitis.
- Appendicitis.

Your cholesterol and fat levels in the blood could go up with Tofacitinib. However, these levels tend to come down after you have had the treatment for a while and do not cause heart attacks.

Do I continue my other treatments for inflammatory bowel disease whilst on Tofacitinib?

Some treatment that you take at present will need to be stopped whilst you are taking Tofacitinib. Your specialist doctor or IBS specialist nurse will advise you whether you should change your other treatments for your inflammatory bowel disease.

Can I take other medication along with Tofacitinib?

This will be discussed with your specialist doctor/IBD specialist nurse.

We need to know all medication you are on as some medication used for other conditions may affect the dose of Tofacitinib that will be given to you.

Do I need any special checks whilst taking Tofacitinib?

Certain blood tests will need to be taken at four weeks, eight weeks after commencing Tofacitinib, then thereafter three monthly.

What will happen if I decide not to have treatment with Tofacitinib?

Your symptoms will continue or worsen. Your specialist doctor will discuss other options for treatment with you.

Can I take Tofacitinib if I am pregnant?

No you cannot take Tofacitinib if you are pregnant or breast feeding. Please use appropriate contraception whilst taking Tofacitinib. If you become pregnant please inform your specialist doctor/IBD specialist nurse immediately.

Can I drink alcohol on Tofacitinib?

Yes, it is safe to drink alcohol while you are taking Tofacitinib, however large quantities of alcohol should be avoided.

Can I have vaccinations while on Tofacitinib?

Flu vaccinations are safe on Tofacitinib. However 'Live' vaccines such as polio, BCG(Tuberculosis), shingles, chicken pox, yellow fever, MMR (measles),mumps and rubella are best given before starting Tofacitinib.

If you need a 'Live' vaccine and you are taking Tofacitinib please contact your specialist doctor/IBD specialist nurse immediately for advice.

Where can I obtain further information about Tofacitinib?

If you have any questions about Tofacitinib, ask your specialist doctor or your IBD specialist nurse.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Inflammatory Bowel Specialist Nurses

Tel: 0151 706 2659

Text phone number: 18001 0151 706 2650

Email: IBDnurses@rlbuht.nhs.uk

Website: crohnsandcolitis.org.uk/mersey

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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