

This video aims to answer common questions you may have if you have been prescribed infliximab or adalimumab to treat your Inflammatory Bowel Disease.

Infliximab and Adalimumab are biological medicines used to treat active Crohn's Disease and ulcerative colitis in adults and in children. They are together called anti-TNF drugs, and are within the group of medicines called "biological drugs".

They work by targeting a protein in the body called TNF alpha. This protein is made as part of the body's response to infection. However, in people with IBD, too much TNF alpha is produced, and this causes inflammation. These drugs block the action of TNF alpha, and reduce inflammation.

You may begin to feel better within a few days or it may take between two to six weeks after your first treatment.

Infliximab is given as an IV infusion – through a drip into a vein in your arm. It cannot be given as tablets because your digestive system would destroy it.

Infliximab infusions are usually given in hospital.

You will probably be treated as a day patient (unless you are already in hospital) and will be able to have the infusion while sitting in a chair. You will be closely observed during the infusion.

Adalimumab is given as a subcutaneous injection, an injection under the skin. To begin with, a doctor or nurse will give you the injections. Once you are used to having the treatment, you may be able to self-inject, if you and your doctor feel this is appropriate, and after you have had the proper training.

Some hospitals have a home care service which may deliver the drug to you directly.

To treat the inflammation effectively, loading doses are given at the start of your treatment.

For infliximab - most people with IBD have their first infusion of infliximab ("week 0") followed by another infusion two weeks later ("week 2") and a third four weeks after that ("week 6"). If you respond well to the treatment, it is likely you will be put onto a maintenance programme. For infliximab this means having an infusion every eight weeks. If there has been no improvement after your loading doses, then alternative treatment may be sought.

For adalimumab, loading doses given by most hospitals will be 160mgs on the first occasion, followed by 80mgs two weeks later. Maintenance treatment is usually 40mgs every other week.

If treatment is effective for you most patients will remain on treatment and this will be reviewed each year. It is very important that you attend all your appointments to ensure the medication is effective and safe for you.

Although not everyone responds to anti TNF drugs, they usually are effective at improving symptoms and in bringing about and maintaining remission. It can reduce the need for admission to hospital and surgery and reduce the risk of Crohn's returning after surgery, as well as successfully helping to heal fistulas.

In some people, anti-TNF drugs can lose effectiveness over time. This means that to have the same benefit the dose has to be increased or given more often. If you have lost response and still have ongoing inflammation, then another option can be to switch to another medicine.

You will have screening blood tests and a chest X-ray to rule out infections, including hepatitis B and C, HIV and TB, before starting treatment but it is important that the treating team know

- If you have any history of tuberculosis (TB) or any recent contact with TB.
- If you have ever had HIV, hepatitis B or C (viral liver infections) or have recently been in close contact with someone who has hepatitis B or C.
- If you are not already immune to chicken pox or measles.
- If you have heart problems in particular heart failure.
- If you have a history of cancer.
- If you smoke, or have Chronic Obstructive Pulmonary Disease
- If you have a fistula or an abscess. Anti-TNF drugs can help to heal fistulas but any abscess must be drained before treatment with anti-TNF drugs.
- If you or a close relative have ever had a disease that affects the nervous system such as multiple sclerosis.
- If you currently have an infection or have symptoms such as feeling feverish or generally unwell. If you have an infection your treatment may need to be postponed.
- If you are pregnant, planning to get pregnant, or are breastfeeding.
- If you are going to have any operations or dental treatments.

Once your treatment has started you will continue to need regular blood tests and review in clinic.

It is also important that you tell your doctor or the hospital team monitoring your treatment about any new symptoms you notice, whenever they occur.

At some hospitals you may also be given a special blood test to check the level of anti-TNF medication in the blood and a stool test to measure the amount of inflammation in the bowel. This helps your team to know how well the medicine is working and whether a change in dose is needed.

If you are on another immune suppressant medicine you might need more frequent monitoring.

- While you are on treatment, try to avoid close contact with people who have infections. Even a mild infection such as a cold or sore throat occasionally develops into a more serious illness when you are on this treatment. Contact your doctor if you begin to feel unwell and think you may have an infection. If you have an infection you should not receive your infliximab or adalimumab until the infection has cleared.
- You may also be at greater risk of becoming seriously ill if you become infected with chickenpox, shingles, or measles. Tell your doctor if you come into contact with anyone with these conditions.
- You should have the annual flu vaccine and pneumococcal vaccine while on anti-TNF treatment. You should not have any 'live' vaccines.
- When in the sun you should wear a hat and use high factor sun cream.
- Be sure to attend when called for any routine screening tests you are offered such as cervical screening or bowel cancer screening.
- Consider carrying or wearing medical alert identification to show you are taking anti-TNF medication. Your hospital may give you a patient alert card to carry.

Like all medicines, anti-TNF drugs can have side effects, although not everyone experiences these. Some side effects can happen almost immediately. Others may not appear for several days, weeks or even longer.

Some side effects are mild and will go away on their own, while others may be more serious and will require treatment.

Side effects of anti-TNF drugs may include the following:

- An allergic reaction - this would usually happen during or soon after your treatment. Tell the hospital staff treating you if you have any of the following:
 - hives or other skin rashes
 - difficulty swallowing or breathing
 - pains in your chest or muscles or joints
 - fever or chills
 - swelling of the lips, face or hands

- headaches or a sore throat
- A greater chance of suffering from infections as mentioned earlier. Tell your doctor if you begin to feel very tired or have a fever, a cough, flu-like symptoms or warm, red, painful skin.
- Skin reactions such as psoriasis, when the skin develops red scaly patches, rashes, ulcers and hives. Tell your doctor if you develop any of these symptoms.
- Blood problems. Your body may not make enough of the blood cells that help fight infections or help to stop bleeding. Symptoms include a fever that does not go away, bruising or bleeding very easily, sore throat, or looking very pale.
- A worsening of a heart problem. Let your doctor know if you notice any new symptoms such as shortness of breath, swelling of the ankles or sudden weight gain.
- An increased risk of developing certain types of cancers including lymphoma (which affects the lymph glands) and skin cancer. You may be more at risk if you are also taking immunosuppressive drugs such as azathioprine or methotrexate and it is more common in young men. However, it is difficult to know exactly what the risk is, as these cancers happen only rarely and very few people are affected. Anti-TNF therapy may not be advised if you have had a cancer in the past.
- Very rarely, nerve damage occurs. Tell your doctor if you get any numbness, tingling or problems with your sight.
- Other rare side effects include liver problems, headaches, abdominal pain, nausea, joint pain, and fatigue, eye problems and depression.

Let your IBD team know about any new symptoms you develop while on anti-TNF drugs, whenever they occur.

This is not a complete list of side effects of anti-TNF drugs; if you do have any questions about this or other aspects of your treatment please discuss this with your IBD team.

The decision to start anti TNF drugs ultimately lies between you and your team treating your inflammatory bowel disease. Anti TNF treatment carries risks, but so does leaving your IBD untreated. Untreated large bowel inflammation (colitis) can increase the risk of bowel cancers, and untreated Crohn's inflammation can allow fistulas, bowel narrowing or infections to develop. Anti TNF medications are a very good way of treating the inflammation and reducing the chance of you going on to develop short or long term problems as a consequence, including surgery.