

Patient Information
Drugs for Inflammatory Bowel Disease –
Infliximab

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Infliximab is used to treat severe Crohn's Disease. It may be given to you when other drugs have not worked or have caused major side effects, and when surgery is not considered the right treatment option for you. Occasionally, Infliximab can be used in the treatment of acute severe ulcerative colitis.

What is Infliximab?

This drug works by reducing inflammation. A protein called TNF-alpha is an important protein in inflammatory diseases and this protein is blocked by Infliximab. This drug has been used to treat many patients with Crohn's Disease and Ulcerative Colitis as well as other conditions such as Rheumatoid Arthritis.

How often do I have Infliximab?

Infliximab is given as an infusion (drip) into the vein, which means having a drip in your arm or the back of your hand. It is usually infused over two hours and you will need to stay in hospital for approximately two hours after the infusion has finished, so you can be monitored for any side effects before being discharged home. This is done in the day area on C4 West at the Royal Gwent Hospital or Ward 4/3 at Nevill Hall Hospital. If you are an inpatient you may receive an infusion as part of your treatment plan before you are able to go home.

Following the first infusion, you will usually have further infusions two and six weeks later. If you are responding adequately, a decision will then be made to decide if you will be given the infusions every eight weeks.

Treatment is usually given for a year to start with but can continue long term. After four successful Infliximab infusions without any side effects, the infusion can be given more quickly.

This is an unlicensed method of administration, but means that you will not have to wait as long for the infusion to finish. The doctor or nurse will discuss with you whether you are happy for this to be done.

We will review the need for continuing treatment with you usually after 3 infusions then after one year.

What dose of Infliximab do I have?

The dose of Infliximab you receive is based on your weight. You will usually receive a dose of 5mg/kg (5 milligrams per kilogram) but this may be increased to 10mg/kg.

How long will it take to work?

The response to treatment varies. Most people feel better within two to six weeks. Some people find they are better within a few days. Some patients do not respond to Infliximab in which case other treatment will be discussed.

How do I know it is safe for me to receive Infliximab?

Before you are able to receive the drug there are a number of questions you will be asked to ensure that Infliximab is safe for you. This will include questions about your general health, any medication you are taking and vaccines you have received in the past.

You will be advised to have a flu vaccine every year, and also a vaccine for pneumonia. In some cases other vaccines may also be advised.

Do I need investigations before commencing Infliximab?

Yes. You will need to have some up to date blood tests and may also have tests for Hepatitis B and HIV (these are viral infections). If you have not had chicken pox you will also need a blood test to see if you are immune.

You will need to have a chest X- ray within the 3 months before starting Infliximab. This is to ensure that you do not have Tuberculosis (TB), as Infliximab can, in some cases, re-activate old TB. If necessary a blood test to check for underlying TB will be arranged. It takes a few weeks to get the results of this test before treatment can be started.

What are the benefits of Infliximab?

Infliximab can be useful for treating severe Crohn's Disease and keeping it under good control. It may be used when other treatments have failed.

Infliximab is used in ulcerative colitis when you have not responded to other medical treatments, or have had a severe relapse. It may be used to make you better before discussing surgery.

What are the side effects?

General side effects

Side effects are uncommon (fewer than one in ten people) and usually mild. With Infliximab, they are more likely to happen during the infusion, or in the few days afterwards.

Other common side effects include: blocked or runny nose, headache, shivering, flushing or rash, swelling of hands, feet, lips or mouth, difficulty in swallowing or breathing, nausea, diarrhoea or abdominal pain.

Rarely, patients have an allergic reaction. If these occur during the Infliximab infusion, the infusion will be stopped. It may be possible to restart the infusion at a lower rate depending on your symptoms.

If you develop these symptoms, you must tell your doctor immediately or contact your specialist nurse.

Infections

Because Infliximab works by suppressing the immune system the risk of infections are increased. Some patients develop simple infections such as a common cold, while other patients have had more severe infections such as pneumonia. Rarely, serious infections including septicaemia (infection of the blood) have been reported with Infliximab.

If you are unwell on the day of treatment, such as suffering from a cold or have a high temperature, you must tell your nurse or doctor.

This is important, as it may be necessary to delay treatment until you are feeling better.

If you come into contact with someone with chicken pox or shingles, you should see your family doctor (GP) immediately and contact your IBD Specialist Nurse as you may need to attend hospital to have a blood test and start treatment.

Some patients have had reactivation of Hepatitis B virus after starting on Infliximab. You should tell us if you have had Hepatitis B in the past or have been in contact with someone who has had Hepatitis B.

There have been cases of Tuberculosis (also called TB: a type of bacterial infection) reported in patients treated with Infliximab and some have led to death. Although the risk is unknown, it is possible that you may have a higher chance of getting TB whilst on Infliximab. If you, or any close members of your family, have a history of TB you should tell your doctor or IBD Nurse. We perform checks to see if you have been exposed to TB before you start on Infliximab.

Other side-effects

A few patients on Infliximab have developed certain abnormal blood results and some symptoms (such as fever, weight loss, muscle or joint pain or a rash) that are found in patients with an immunological condition called Systemic Lupus Erythematosus (SLE). All patients recovered after treatment was stopped.

If you have a history of heart failure (also known as congestive cardiac failure or left ventricular failure) then Infliximab treatment may increase the risk of worsening heart failure and other treatments may be more appropriate.

Skin reactions including psoriasis have occasionally been reported with Infliximab treatment. You should also avoid becoming sunburnt by covering up in the sun and using sun tan cream as there may be a slightly increased risk of some forms of skin cancer.

Other rare side effects have been reported on the nervous system with features similar to Multiple Sclerosis. Likewise, it is possible that Infliximab could worsen Multiple Sclerosis, and should not be given to people who have a history of this. You should tell your doctor or IBD Nurse if you have ever been diagnosed with Multiple Sclerosis.

There have been rare reports of people developing cancer whilst on Infliximab. These include cancers of the blood such as Lymphoma and Leukaemia. However, most of these people have been on other drugs (such as Azathioprine, Mercaptopurine or Methotrexate) which are known to increase the risk of these cancers. Therefore it is difficult to know the contribution Infliximab has to these cancers developing. It is difficult to give a precise risk, but it is rare (less than 1 in 1000).

Are there alternative treatments available?

This should be discussed with the consultant responsible for your care as well as your IBD nurse. Other drug treatments may be available or surgery may be an option. You should continue with your usual medication until you are told to stop it.

What If I decide not to have Infliximab?

If you decide not to have Infliximab then alternative treatments will be discussed with you. These may not work as well as Infliximab and may also have side effects. These may not work as well as Infliximab and may also have side effects. The risk of needing an operation may be increased and this may result in the need for a stoma (bag) formation.

Do I continue my other medications for Inflammatory Bowel Disease?

Usually, yes, but please discuss this with your doctor or IBD Nurse when you come for the infusion.

Can I take other medication along with Infliximab?

Yes, all the medications used to treat Crohn's Disease and Ulcerative Colitis can be used together with Infliximab. Please tell your doctor or IBD nurse about any medicines you are taking, including any you have bought yourself. You will be told if you need to stop any.

Do I need any special checks following Infliximab?

You will have a blood test before each infusion. Infliximab and other medications you may be taking can lower your resistance to infection. You should tell your GP or IBD Specialist Nurse if you develop a sore throat, fever (high temperature) or any other infection and may be advised to have an extra blood test at this time.

Try to avoid contact with people who have infections where possible as you may be at risk of severe infection from the germs which cause chickenpox, shingles, influenza (flu), measles and pneumonia. If you come into contact with anyone who has any of these conditions, tell your doctor or nurse as soon as possible.

Can I have immunisations after having Infliximab?

You should have a flu vaccine every year. Flu vaccinations are safe following Infliximab treatment. You should also have a Pneumovax vaccine to protect against some forms of pneumonia. Your practice nurse or GP will arrange these for you.

You should avoid 'live' vaccines such as polio, BCG (Tuberculosis), MMR (measles, mumps and rubella). An 'inactive' polio vaccine can be given instead of a 'live' one if this is needed. An 'inactivated' version should also be given to those with whom you are in contact.

If you require vaccinations, please let your doctor or practice nurse know that you are receiving Infliximab treatment.

Can I drink alcohol following Infliximab?

There is no reason to avoid alcohol in moderation.

Does Infliximab affect fertility or pregnancy?

Please inform your Consultant or IBD Specialist Nurse if you are planning to have a baby so that your medication can be reviewed.

Infliximab is felt to be safe in the first three months of pregnancy but should not be given in the last 3 months of pregnancy. However, there is not much evidence available. Generally it is better to avoid pregnancy for **at least six months** after the last dose. Men should not try for a baby with their partners for at least **six months** after having the last dose. If you are thinking of having a baby please discuss this with your consultant or IBD nurse. If you find you are pregnant please let your IBD nurse know so a clinic appointment can be arranged to discuss your medication.

What about breastfeeding?

Information on whether breastfeeding is safe if you are having Infliximab is limited, therefore it is better to avoid breastfeeding whilst on Infliximab and for 6 months after your last dose.

Where can I obtain further information about Infliximab?

If you have any questions about Infliximab, ask your doctor, IBD Specialist Nurse or your pharmacist.

Please contact the IBD Nurse Specialists:

Allyson Lewis, Lead Clinical Nurse Specialist (IBD)

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On the following number:- 01633 656055 – answer phone or email:- IBDHelp@wales.nhs.uk if you require further information.