

Infliximab medication in inflammatory bowel disease

The aim of this leaflet is to give young people, parents and carers information about Infliximab.

Why do I need a new medicine?

Infliximab is a relatively new medicine. It is used to treat severe Crohn's disease. It may be given to you when other medicines have not worked or have caused bad side effects and when surgery is not the right treatment for you.

Infliximab may be used for people who have fistulas that have not healed with other medical or surgical treatments.

Infliximab is also occasionally used to treat ulcerative colitis when the colitis is severe and has not improved with steroid treatment.

What does Infliximab do?

Infliximab targets a protein in the body called TNF-alpha (tumour necrosis factor-alpha). Your body produces TNF-alpha as part of its immune response, to help fight infections. In people with inflammatory bowel disease, too much TNF-alpha is made, which can cause damage to the intestine (bowel). Infliximab sticks to TNF-alpha, which stops it causing the damage.

How do I take Infliximab?

Infliximab needs to be given in hospital. This will usually be on the Day Stay ward. It takes about two hours to give the infliximab, but you will also need to stay for two hours afterwards to make sure you are OK.

Infliximab is infused (dripped) through a tiny plastic tube (luer) into a vein in your hand or arm. The infliximab is mixed with salt water and flows from a bag through some plastic tubing straight into your vein.

Will I start feeling better straight away?

Infliximab does often work quite quickly. Children usually begin to feel better after the first or second dose. You will be seen by your doctor soon after starting the Infliximab to ensure that you are feeling better.

Are there any side effects of Infliximab?

Some patients experience an allergy like reaction while or shortly after getting the infusion. This can be:

- Fever
- Chest pain or joint pain
- Breathlessness
- Sore throat
- Rash
- Swelling of the face
- Headache.

If you experience any of these symptoms please get the attention of a doctor or nurse immediately. To reduce the chance of you getting any side effects, you will be given some steroid and anti-allergy medicine before you get the Infliximab.

Other rare side effects include:

- Heartburn,
- Diarrhoea
- Constipation
- Inflammation of the liver, gallbladder, pancreas and stomach.

Will I be at a higher risk of catching infections while taking infliximab?

Infliximab does reduce your body's defense against infection, so you may be at increased risk for some infections. Chicken pox can be a serious infection while you are taking infliximab. We will check a blood test to see if you are protected against chicken pox before you start the infliximab. If you have had chicken pox in the past, your body will have developed antibodies that will protect you against the infection, even when you are on infliximab. If you do not have antibodies to chickenpox, we will tell you what to do if you come into contact with anyone that has chicken pox while on infliximab. There are also some vaccinations (called "live" vaccines) that you can't have while taking infliximab. So if you are due any vaccinations you must tell the doctor or nurse that you are taking infliximab and they can advise you if the vaccination is safe.

Tuberculosis is an infection which can be dangerous if you are taking infliximab. Tuberculosis can cause a serious infection in your chest and occasionally other parts of the body. Fortunately, tuberculosis is not common in New Zealand, but it is more common in other parts of the world. It is really important to tell your doctor if you have been in contact with anybody who has Tuberculosis.

When receiving Infliximab there may be a small risk of developing tumours such as lymphomas in later life.

- It is important to remember that Infliximab is only used if it is absolutely necessary.

What other precautions are necessary?

- Regular blood tests are needed to pick up side effects early. These are done weekly for 2 weeks, then twice monthly for 2 months, then once monthly thereafter.
- Do not take any other medications without informing your doctor. This includes over the counter and herbal medicines.
- Chickenpox and shingles: If you have contact with somebody with chickenpox or shingles let your general practitioner or hospital doctor know **immediately** as you may need treatment to prevent you getting chickenpox.
- Although unlikely in our patient group patients should not become pregnant while on treatment with Infliximab and for six months after the last dose of Infliximab.

Vaccinations

A yearly flu vaccine should be given while on this treatment. This can be arranged at the hospital or your general practice each autumn.

Make sure you tell all your doctors and nurses that you are taking Infliximab. You should **not** receive any **live** vaccines during treatment with Infliximab and for six months afterwards. (This includes MMR, yellow fever and BCG). Close relatives and family members may have live vaccines as normal. Speak to your nurse or doctor for advice.

How long will I need to take Infliximab for?

The honest answer is that we don't really know at the moment. If it helps you, then we will want you to stay on it for at least six months. You have some important years coming up, during which you may need to grow, develop into an adult, take exams and start a job. It is important that you are as well as possible during these years and that we try to use as little steroid medicine as possible. So, if the Infliximab works for you, it may be best that you continue taking it during this time. Your gastroenterology doctor will see you regularly while you are on the Infliximab and will talk to you regularly about whether you need to continue taking it.

Do I have to start the Infliximab medication?

The doctor has recommended Infliximab because it has a good chance of making you better.

You and your parents do have a choice though and can choose not to have the new medicine if you don't want to. If you want more time to think about it, then take this leaflet home and let us know your decision in the next few days.

Who do I contact if I have any questions?

Please contact the paediatric gastroenterology team at Starship Hospital via the Secretary Dani Ta'ase on 09 3074949 Ext 5471.