

Infliximab infusions for juvenile arthritis and uveitis

Information for
Parents, Carers & Young
People



leeds children's
hospital

caring about children

Introduction

This leaflet contains information about the use of infliximab infusions in children with juvenile arthritis and uveitis. It is also used for other rheumatological conditions e.g. juvenile dermatomyositis and systemic vasculitis.

It tells you:

- how the medicine works
- how it should be given
- whether there are any side effects.

Please also read the general information leaflets available at <http://www.medicinesforchildren.org.uk>

Why have I been given this leaflet?

The information in this leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with this treatment.

For most medicines, information is provided by the manufacturer in the medicine package. However, this medicine does not have a licence for use for juvenile arthritis in children. This means that the information provided by the manufacturer does not tell you everything you need to know. So we have written this leaflet to give you some extra information.

What is infliximab infusion and how does it work?

Infliximab is a monoclonal antibody which is active against TNF α , a protein in the body which is thought to cause inflammation in juvenile idiopathic arthritis and uveitis. Infliximab is believed to reduce the activity of TNF α , therefore reducing the inflammation associated with these conditions.

How should I give infliximab?

Infliximab will be given as an infusion into the vein: through a cannula (drip). The initial course of treatment will involve three infusions given over six weeks (at 0, 2 and 6 weeks).

After this, infusions will be given at four to eight weekly intervals depending on exact condition and response.

It is important to take another disease modifying drug such as methotrexate regularly when on infliximab, as this reduces the risk of infliximab stopping working.

When should infliximab infusion not be used?

- You/Your child should not receive this medicine if they have a history of hypersensitivity to infliximab or they have tuberculosis or other severe infections such as abscesses.
- As long as you/your child is unwell with fever, or usually if needing antibiotics, the infliximab infusion should be delayed.
- This medicine should be used with extra care if you/your child has a history of cancer, liver or kidney problems, or disorders of the nervous system.

Please discuss contraception or planning a pregnancy with your doctor or nurse. They can give you information on what risks the medication may cause to you and your baby.

If you think there is a possibility that you are pregnant or your partner may be pregnant please contact your nurse specialist or family doctor immediately.

Are there any side effects?

All medicines can cause side effects. During or for a short time after the infusion, infliximab can sometimes cause raised temperature, low or raised blood pressure, itching with or without a rash and change in bowel habits.

Infliximab produces an effect on the immune system, therefore you/your child might get infections more easily e.g. colds or chest infection. Very occasionally this prompts stopping of infliximab. Contact your doctor if you think that your child has developed an infection.

As with all immunosuppressant medication, we would recommend safe sun exposure, and in particular avoiding sun burn, due to an increased risk of long term skin damage.

Everyone reacts differently to medicines. It is very unlikely that you/your child will have all the effects listed above. Blood tests will be taken before each infusion of infliximab to make sure you/your child is able have the medicine.

Will infliximab affect any other medicines?

Tell your doctor or pharmacist about all the other medicines you/your child takes. This includes any medicines prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

If you/your child is prescribed a new medicine, or you want to buy a medicine (for your child), it is important that you tell the doctor or pharmacist about all the medicines that you take, including infliximab. You should also tell your dentist next time you see him/her.

Caution may be required when you/your child requires a vaccine. Patients on infliximab should NOT have a live vaccination and this will need to be discussed with your doctor.

Please arrange an influenza vaccine every winter, due to the immunosuppressive nature of the medicines. You may also need a pneumococcal vaccine.

So this medicine does not have a licence. What does this mean?

The leaflet called unlicensed medicines available at <http://www.medicinesforchildren.org.uk/> tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used.

Why does infliximab infusion not have a licence for use in children?

Sometimes a medicine has been licensed for a certain use in adults and later experience or research shows that it works for a similar condition in children. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money and in some situations it is not economical for the manufacturer to obtain or extend a licence.

Infliximab infusion is made by the manufacturer for management of rheumatoid arthritis, Crohn's disease, ankylosing spondylitis and psoriatic arthritis in adults. It is also licensed in children for the management of Crohn's disease.

Remember that your doctor will have thought carefully about which medicine is best for your child's condition.

Why do I need to agree for my child to take this medicine?

Your agreement should be obtained before prescribing any medicine for you/your child. This leaflet has explained that infliximab does not have a licence in the UK and provided information about possible side effects. You will have the chance to ask questions and then you will be asked to say whether or not you want to take this medicine/give this medicine to your child.

If you agree, but later decide that you don't want you/your child to have infliximab infusion after all, that is fine. Please tell your doctor.

How can I find out more?

This leaflet has been written to provide general information about the use of infliximab in children. If you have any more specific questions or concerns, please speak to one of the following:

Useful contact numbers

Children's Rheumatology Nursing Team	0113 392 0683
Paediatric Rheumatology Secretary	0113 392 0666



What did you think of your care? Visit bit.ly/nhsleedsfft
Your views matter

© The Leeds Teaching Hospitals NHS Trust • 2nd edition (Ver 1)
Developed by: Paediatric Rheumatology Team
Produced by: Medical Illustration Services • MID code: 20231009_010/EP

LN001824
Publication date
10/2023
Review date
10/2026