



Etanercept for juvenile idiopathic arthritis

This leaflet is about the use of etanercept for juvenile idiopathic arthritis (which is often shortened to JIA).

This leaflet is for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adults. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Do not stop giving etanercept suddenly, as your child may have a seizure (convulsion or fit).

Name of drug

Etanercept

Brand name: Enbrel

Why is it important to take this medicine?

Etanercept helps to reduce the inflammation (swelling) and pain in the joints of children with juvenile idiopathic arthritis (JIA). It is used if treatment with another drug has not worked as well as it was hoped or it had bad side-effects.

Etanercept works by reducing levels of a protein called tumour necrosis factor (TNF). The amount of TNF in the blood can be too high in inflammatory conditions like JIA.

What is etanercept available as?


Subcutaneous injection: 25 mg or 50 mg pre-filled syringe. The medicines for injection contain sucrose.

When should I give etanercept?

Etanercept is usually given **once or twice a week**. Your doctor will tell you which days to give the medicine. You can write these days in your diary to remind you and so that you have a record of when you last gave it.

How much should I give?

Your doctor will work out the amount of etanercept (the dose) that is right for *your* child. The dose will be shown on the medicine label.

 **It is important that you follow your doctor's instructions about how much to give.**

How should I give it?

Etanercept has to be given as an injection underneath the skin (this is called a subcutaneous injection). Your doctor or nurse will show you how to do this. Older children may be able to do this for themselves. Injections are usually done in the top of the leg or the abdomen. It is best to inject the needle into a slightly different area of skin each time, so that there is less chance of bruising or a reaction to the injection.



When should the medicine start working?


Your child should start to have less pain and inflammation when they have been taking etanercept for 2–12 weeks. Your doctor will decide whether it is working once your child has been taking it for a few weeks. It is therefore important that you continue to give it as your doctor has told you to.

What if my child is sick (vomits)?


You do not need to worry if your child is sick, as the medicine will still work.

What if I forget to give it?

Do the missed injection as soon as you remember, unless this is the day before the next dose is due, in which case do not give the missed dose.

 Do not give more than one injection in a 24 hour period.

What if I give too much?


 It may be dangerous to give too much etanercept.


If you think you may have given your child too much etanercept, contact your doctor or local NHS services (details at end of leaflet) or take your child to hospital. Take the medicine container or packaging with you, even if it is empty. This will be useful to the doctor. Have the medicine or packaging with you if you telephone for advice.

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects). If you are worried, contact your doctor.

Side-effects you must do something about

 If your child is short of breath or is wheezing, or their face, lips or tongue start to swell, or they develop a rash, they may be allergic to etanercept. Take your child to hospital or call an ambulance straight away.

 Etanercept occasionally causes serious side-effects. These are unlikely, but you should contact your doctor straight away if your child has any of the following symptoms:

- Your child has a rash and is also generally unwell and has a fever (high temperature above 38°C) with cough, shortness of breath, chills, weakness or red, hot tender areas over the skin or joints. This may indicate a serious infection.
- Your child is pale and seems to bruise more easily or bleeding doesn't stop as quickly as you would expect.
- Your child feels numbness, weakness or pins and needles in their arms or legs, or there is a change in their vision or they have eye pain, or have a fit.

Other side-effects you need to know about

- If your child has pain when they urinate (do a wee) or any difficulty urinating, contact your doctor.
- Your child may get a skin infection, or develop psoriasis (red and white scaly patches on the skin) or blistering of the skin. If you are worried, contact your doctor.
- Your child may develop itchiness or a rash. Try applying a moisturising cream or anti-itch cream. If this does not help, contact your doctor, in case your child is allergic to etanercept.
- Your child may have some swelling, bruising or pain at the site of injection. This is usually worst in the first month of treatment. To help avoid this, do each injection in a slightly different place.
- Your child may feel sick or be sick (vomit) or have some stomach pain or diarrhoea. If this is still a problem after 2 weeks, contact your doctor.
- Your child may get headaches.


There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at www.mhra.gov.uk/yellowcard.

More information on side-effects can be found in the following leaflet <http://www.medicinesforchildren.org.uk/side-effects-childrens-medicines>


Can other medicines be given at the same time as etanercept?

- You can give your child medicines that contain paracetamol or ibuprofen, unless your doctor has told you not to.
- Etanercept should not be taken with some medicines that you get on prescription. Tell your doctor and pharmacist about any other medicines your child is taking **before** giving etanercept. This includes herbal or complementary medicines.


Is there anything else I need to know about this medicine?

 Do not suddenly stop giving etanercept to your child, as your child may have a seizure (fit or convulsion).

- Your doctor will test your child's blood regularly to check that etanercept has not affected their blood.
- Etanercept affects your child's immune system so they may get more infections such as chest infections, coughs and colds and they may take longer to fight these off. Try to keep your child away from people with infections if you can, but they can still attend school and nursery.

 If your child comes into contact with anyone who has measles, chickenpox (or shingles), contact your doctor straight away, as they may need special preventative treatment.


- Your child may have an increased risk of getting tuberculosis (TB). If your child loses weight, has a fever (high temperature) or develops a cough that will not go away, these could be symptoms of TB. If your child has had TB before starting the medicine your doctor will check them regularly to make sure it has not come back.

 If your child is due to have a vaccination, tell your doctor or nurse they are taking etanercept. Some vaccines should not be given.

- If you or your child want to stop this medicine, discuss this with your doctor. They will explain how to reduce the dose bit by bit. Do not reduce the dose without discussing this with your doctor.
- If your child takes etanercept for a long time, there is a low risk of skin cancer. Tell your doctor if you notice any unusual spots or sore patches on your child's skin.

General advice about medicines

- If you are not sure a medicine is working, contact your doctor but continue to give the medicine as usual in the meantime. Do not give extra doses, as you may do harm.
- Only give this medicine to *your* child. Never give it to anyone else, even if their condition appears to be the same, as this could do harm.

 If you think someone else may have taken the medicine by accident, contact a doctor straight away.

- Make sure that you always have enough medicine. Order a new prescription at least 2 weeks before you will run out.
- Make sure that the medicine you have at home has not reached the 'best before' or 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

Where should I keep this medicine?

- Keep the syringes in the container they came in and put them in a fridge. Make sure that the liquid doesn't freeze.
- Make sure that children cannot see or reach the medicine or syringes.
- The used syringes should be thrown away into a sharps box. Your doctor or pharmacist will give you this and tell you how to use it.

Who to contact for more information

Your doctor, pharmacist or nurse will be able to give you more information about etanercept and about other medicines used to treat JIA. You can also get useful information from:

England: NHS 111 - Tel 111 - www.nhs.uk

Scotland: NHS 24 - Tel 111 - www.nhs24.scot

Wales: NHS Direct - Tel 111 - www.111.wales.nhs.uk

Northern Ireland: NI Direct - www.nidirect.gov.uk

Children's Chronic Arthritis Association

01905 745 595 - www.ccaa.org.uk