



Tocilizumab



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Patient information

Tocilizumab belongs to a group of medicines called biologic disease modifying anti-rheumatic drugs (biological DMARDs).

Tocilizumab works by blocking the action of an inflammatory protein called Interleukin 6 (IL-6). In patients with juvenile idiopathic arthritis (JIA) there is too much IL-6, which increases inflammation and causes damage to bones, cartilage and tissue. Tocilizumab 'turns off' production of IL-6 and helps prevent this from happening.

Why is Tocilizumab being prescribed for my child?

Tocilizumab is used to reduce inflammation and associated pain and/or damage in conditions like Juvenile Idiopathic arthritis (JIA). It will only be prescribed if the arthritis is active. It may be the first biological drug your child receives, or used after trying others.

How do I use Tocilizumab?

Tocilizumab needs to be given in hospital by intravenous infusion (through a drip into your vein). This is usually done as a day admission and takes about 3-4 hours.

What checks are needed while taking Tocilizumab?

Before starting on Tocilizumab your child will have a blood test to screen for any existing serious infections. They will also have a chest x-ray to check for tuberculosis. Regular blood tests are needed while on Tocilizumab.

How long does it take for Tocilizumab to work?

This can vary between patients but improvement is usually seen in 2-12 weeks.

Are there any side effects?

As with all medicines, Tocilizumab can have side effects. These will be discussed with you in more detail before starting to allow you to consider the benefits and risks.

The more common side effects are respiratory infections (that may include sinus infections and sore throat), headache, dizziness, mouth ulcers, stomach irritation and inflammation around the drip site. These are generally mild. Please notify your doctor if they become a problem.

More serious side effects include:

- Increased risk of serious infection: see over page for more information
- As with all medications, there is a risk of an allergic reaction (fever, chills, hives, feeling sick, chest pain, shortness of breath and/or change in blood pressure): with every infusion your child will be given medicines to help reduce the risk of this
- There may be a small risk of developing tumours such as lymphomas in later life. However, this has not yet been confirmed with research.
- Tocilizumab may affect some blood cells and the liver—regular blood tests are needed to check these.

What should I do about the increased infection risk?

Tocilizumab affects the body's defence against infections, so your child may be at increased risk for serious infections, although this is uncommon. Extra attention to basic hygiene and avoiding contact with contagious illnesses are advised. It is a good idea to speak to your child's pre-school or school and ask them to notify you of any contagious illnesses that may occur.

Chicken Pox, measles and tuberculosis are of serious concern. Please notify your doctor as soon as possible if your child has come into contact with these conditions.

Can I have vaccinations while on tocilizumab?

Tocilizumab may reduce your child's immune response to vaccines, so 'live' vaccines such as MMR (Measles, Mumps and Rubella), oral Polio, and Varicella (Chickenpox) should not be given while on Tocilizumab or for 6 months afterward. Close family members can have these vaccines as normal, and we recommend this to give added protection to your child.

Yearly flu vaccines, and other vaccines such as Tdap (tetanus, diphtheria and pertussis), IPV (inactivated polio vaccine) and HPV (human papilloma virus) are safe and we recommend your child having these.

What other precautions are necessary?

- Regular blood tests are needed to pick up side effects early.
- Do not take any other medications without informing your doctor. This includes over the counter and herbal medicines.
- Although unlikely in our patient group, your child should not become pregnant while on treatment with Tocilizumab and for six months after the last dose.

Please contact your doctor or nurse for advice if:

- Your child has contact with chickenpox, shingles or measles —please notify as soon as possible as your child may need treatment
- Is unwell and/or has a high fever and you don't know why
- If your teenager may be pregnant

How long will I need to take Tocilizumab for?

This varies for each child and is difficult to predict. If Tocilizumab is effective, we would expect your child to need it for a minimum of 6 months. Your Rheumatology doctor will see your child regularly while they are having Tocilizumab and decide whether your child needs to continue taking it.

Do I have to start the Tocilizumab medication?

Your doctor has recommended Tocilizumab because there is a good chance of its controlling your child's arthritis. As with any treatment you can choose not to have the medicine. If you decide to stop it is important that you tell your doctor. Stopping or giving Tocilizumab at intervals longer than recommended may mean that it is less effective. Read the information provided and discuss any questions or concerns you have with your healthcare team.

Please note that this information sheet does not list all the uses and side effects associated with this drug. For full details please see the drug information available at:

<http://www.guildlink.com.au/gc/ws/ro/cmi.cfm?product=rocactem11014>

If you have any further questions, please contact your paediatric rheumatology team.

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