





Tocilizumab should effectively treat your condition, and stop it causing damage to your joints. It has been tested and has helped many people. However, as with all drugs some people will have side-effects. This leaflet sets out what you need to know.

# What is tocilizumab and how is it used?

Tocilizumab is a type of drug called a biological therapy. In rheumatoid arthritis too much of a protein called IL-6 may be produced in the body. This can lead to tiredness, anaemia, inflammation and damage to bones, cartilage and soft tissues. Tocilizumab blocks the action of IL-6, reducing these effects. It isn't a painkiller, but can modify the disease over a longer period. It may be 2–12 weeks before you notice an improvement.

Tocilizumab can be prescribed by a consultant rheumatologist for rheumatoid arthritis or juvenile idiopathic arthritis (JIA).

It may be the first biological therapy you receive, or you may have tried others first, such as an anti-TNF drug or rituximab.

Tocilizumab won't be started if:

- your arthritis isn't active
- you have an infection
- you haven't first tried at least two disease-modifying antirheumatic drugs (DMARDs),

such as methotrexate and hydroxychloroquine. Usually tocilizumab will be prescribed in combination with methotrexate.

Your doctor may decide not to prescribe tocilizumab if you're pregnant or breastfeeding or if you have:

- a condition such as diabetes that makes you more prone to infection
- liver disease or abnormal liver function tests
- low levels of white blood cells (neutrophils) or platelets
- a history of intestinal ulcers or diverticulitis

or if you've had

- repeated or serious infections
- cancer.

Before starting tocilizumab you'll have a chest x-ray and blood tests. Your doctor will check if you've previously

> You should start feeling better within 12 weeks, often sooner.

been exposed to tuberculosis (TB), and you may need a course of treatment for latent (asymptomatic) TB before starting tocilizumab. You'll also be checked for previous hepatitis infection, as tocilizumab may increase the risk of hepatitis being reactivated.

You'll need further cholesterol checks and blood tests every 4–8 weeks while you're on tocilizumab to monitor its effects.

## When and how do I take tocilizumab?

Tocilizumab may be given:

- **either** through a drip into a vein (an intravenous infusion) which takes about an hour once every four weeks
- or as an injection under the skin (a subcutaneous injection) once a week using a pre-filled syringe. You, your partner, or another member of your family can learn to give these injections.

If you're already having infusions and wish to switch to injections you should speak to your rheumatology team – you'll probably start your injections when your next infusion is due.

Because it's a long-term treatment it's important to keep taking tocilizumab (unless you have severe side-effects):

- even if it doesn't seem to be working at first
- even when your symptoms start to improve (as this will help keep the disease under control).

Make sure you attend for your regular check-ups.

### Possible risks and side-effects

The most common side-effects aren't usually serious – they include:

- a cough or sore throat, blocked or runny nose
- headaches or dizziness
- mouth ulcers
- eye inflammation (conjunctivitis)
- high blood pressure
- weight gain or swollen ankles
- skin rashes, infections or itching
- stomach irritation or abdominal pain
- inflammation around the drip site.

Tell your doctor or rheumatology nurse straight away if you have a reaction during or after an infusion or injection.

Tocilizumab can make you more likely to pick up infections. It can also make them harder to spot. Tell your doctor or rheumatology nurse if you develop a sore throat or fever, or have unexplained bruising, bleeding or paleness, or any other new symptoms that concern you. If any of these symptoms are severe, you should stop taking tocilizumab and see your doctor straight away.

You should also see your doctor if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. These can be severe if you're on tocilizumab. You may need antiviral treatment, and your tocilizumab may need to be stopped until you're better.

Tocilizumab can sometimes increase cholesterol levels and you may be asked to consult your GP for treatment to reduce these levels. It can also affect liver function tests or reduce the numbers of white cells, or sometimes platelets, in your blood. You might sometimes need to miss one or more infusions, but it's rare to have to stop the drug altogether.

If you have intestinal ulcers or diverticulitis you may be more at risk of infection, which can sometimes lead to bowel perforation. Tell your doctor immediately if you develop stomach pain, particularly if you have a temperature and you notice changes in your bowel habits, such as passing blood.

The long-term side-effects of tocilizumab aren't yet fully understood, because it's a relatively new drug. There may be a slightly increased risk of certain cancers when using drugs that affect the immune system, such as tocilizumab, though so far research hasn't confirmed this.

#### **Reducing the risk of infection**

- Try to avoid close contact with people with severe active infections.
- For advice on avoiding infection from food, visit: www.nhs.uk/Conditions/Foodpoisoning/Pages/Prevention.aspx

#### **Taking other medicines**

Tocilizumab may be prescribed along with other drugs, including methotrexate. Check with your doctor before starting any new medications, and remember to mention you're on tocilizumab if you're treated by anyone other than your usual rheumatology team.

> If you're having infusions, you may be able to switch to injections you can do yourself.

- You can carry on taking nonsteroidal anti-inflammatory drugs (NSAIDs) or painkillers if needed, unless your doctor advises otherwise.
- Don't take over-the-counter or herbal remedies without discussing it first with your healthcare team.

It's recommended that you carry a biological therapy alert card so anyone treating you will know that you're on tocilizumab – you can get a card from your rheumatology department.

### Alcohol

You can drink alcohol while on tocilizumab, but stay within government guidelines for adults of no more than 14 units per week. If you're also taking methotrexate your doctor may advise lower limits because methotrexate can interact with alcohol and affect your liver.

#### Vaccinations

It's usually recommended that people on tocilizumab avoid live vaccines such as yellow fever. However, sometimes a live vaccine may be necessary – for example, rubella immunisation in women of childbearing age.

If you're offered shingles vaccination (Zostavax) it's best if you can have this before starting tocilizumab. Shingles vaccination isn't recommended for people on tocilizumab.

Pneumococcal vaccine, which protects against the most common cause of pneumonia, and yearly flu vaccines are safe and recommended.

### Having an operation

If you're having an operation you may be advised to stop the tocilizumab for a time before and after surgery – check with your healthcare team.

# Fertility, pregnancy and breastfeeding

We don't yet know how tocilizumab might affect unborn babies but it does not cross the placenta until 16 weeks of pregnancy so is unlikely to be harmful if you are accidentally exposed to it in the early stages of pregnancy. Generally however, women of childbearing age are advised to use contraception during treatment and for three months afterwards. Talk to your doctor if you become pregnant while taking it.

If you are also taking methotrexate you should use contraception for three months after stopping treatment.

We don't yet know whether tocilizumab can pass into breast milk and be harmful to babies. The current advice is not to breastfeed while taking tocilizumab.

## Arthritis Research UK

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We're dedicated to funding research into the cause, treatment and cure of arthritis so that people can live pain-free lives.

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0300 790 0400 www.arthritisresearchuk.org We would like to thank the team of people who contributed to the development of this booklet. It was written by Prof John Isaacs and updated by Dr Ian Giles. An **Arthritis Research UK** medical advisor, Prof Anisur Rahman, is responsible for the content overall.

Please note: we have made every effort to ensure that this content is correct at time of publication, but remember that information about drugs may change. This information sheet is for general education only and does not list all the uses and side-effects associated with this drug.

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