

Drug information  
**Tocilizumab**

## **TOCILIZUMAB**

is used to treat rheumatoid arthritis, juvenile idiopathic arthritis and giant cell arteritis

**VERSUS  
ARTHRITIS**

### Introduction

Tocilizumab (toss-ill-ee-zoo-mab) is a drug that can help prevent your condition causing damage to your body. It can sometimes cause side effects, but many of these are rare or uncommon. You can discuss the benefits and risks of taking tocilizumab with your healthcare professionals before you start treatment, so you're able to make an informed decision.

### What is tocilizumab and how is it used?

Tocilizumab is a biological therapy and can be prescribed for rheumatoid arthritis (roo-ma-toy-d arth-ri-tus), juvenile idiopathic arthritis (JIA) or giant cell arteritis.

If you have rheumatoid arthritis, or another autoimmune or inflammatory condition, there may be too much of the IL-6 protein in your body. This can cause inflammation and damage, and in children can cause a fever and rashes. Tocilizumab works by blocking the effects of IL-6.

Tocilizumab will work within three to six months, if it is going to work at all. Some patients may feel better as early as two weeks after starting treatment.

It may be the first biological therapy you're given, or you may have tried others first, such as an anti-TNF treatment or rituximab.

You won't be given tocilizumab if:

- your arthritis isn't active
- you have a severe infection
- you have not tried other treatments for your condition
- you're pregnant or breastfeeding.

Your doctor may decide not to prescribe tocilizumab if:

- you keep getting infections
- you've had cancer
- you've had liver disease or if blood tests suggest that the drug may affect your liver
- you have a low number of white blood cells or platelets
- you have a history of diverticulitis (die-vuh-tick-yoo-lie-tus)
- you have certain heart problems.

Your doctor will check whether you've previously been exposed to tuberculosis (TB). You may need a course of treatment for latent TB before starting tocilizumab. However, this may not be done if you're a child with systemic onset JIA.

If you're an adult, you will also be screened for hepatitis B and C infection. Tocilizumab may increase the risk of hepatitis B starting up again, although very few cases have been reported. If you have a history of hepatitis, the decision to use tocilizumab may involve a discussion between you, your rheumatologist (roo-ma-tolo-jist) and a liver specialist.

If you're an adult, you may have a chest x-ray before starting tocilizumab. You will also have a chest x-ray six months after starting treatment.

## When and how do I take tocilizumab?

**Table 1:** How to take tocilizumab

	<b>Rheumatoid arthritis</b>	<b>Giant cell arteritis</b>	<b>Systemic JIA</b>	<b>Polyarticular JIA</b>
Sub-cutaneous injection	Yes – this is done once a week	Yes – once a week, in the thigh or upper arm	No	No
Intravenous infusion	Yes – this takes about an hour once every four weeks	No	Yes – every two weeks	Yes – every four weeks

An intravenous (in-truh-vee-nus) infusion is when the drug is given through a drip into a vein.

A subcutaneous (sub-kyoo-tay-nee-us) injection is when the drug is injected under the skin, using a pre-filled syringe or a pen device.

If you're already having infusions and want to switch to injections, speak to your rheumatology team.

Because it's a long-term treatment, it's important to keep taking tocilizumab:

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

However, this may change if you experience side effects.

## Possible risks and side effects

The most common side effects are:

- a cough or sore throat, blocked or runny nose
- headaches or dizziness
- mouth ulcers
- high blood pressure
- increased cholesterol in the blood
- allergic reactions – this can include aching muscles, feeling out of breath, having a tight chest, wheezing, and a high temperature
- weight gain or swollen ankles
- skin rashes, infections or itching
- stomach irritation or abdominal pain.

Tocilizumab has been shown to increase the risk of infections in patients with rheumatoid arthritis. These include:

- upper respiratory tract infections
- cold sores
- shingles
- skin infections – such as cellulitis (sel-lyu-lie-tus)
- pneumonia (new-mow-nee-uh).

It is important that any infections are treated as soon as possible.

If you think you may have an infection, or you become unwell in any way, contact your rheumatology team or your GP. People taking tocilizumab do not always display the usual signs of infection, such as a high temperature, as they are blocked by tocilizumab. Seek advice if you're unsure.

If you're prescribed antibiotics, speak to your rheumatology team and cancel your tocilizumab infusion. Temporarily stop your injections until the infection has cleared up.

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If you're living with HIV, hepatitis B or hepatitis C, it is important that you discuss any potential risks of taking tocilizumab with your rheumatologist.

### Cholesterol and liver function

Tocilizumab can increase your cholesterol levels and can also affect liver function tests. As a result, you will need a blood test every four weeks while taking tocilizumab.

### Dizziness

You may feel dizzy while taking tocilizumab. This could affect your ability to drive and perform other tasks.

## Taking other medicines

Tocilizumab may be prescribed along with other drugs, including methotrexate (mee-thoh-treks-ate) and glucocorticoids (steroids). 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.

### In rheumatoid arthritis

Tocilizumab can be taken for rheumatoid arthritis if:

- your arthritis is severe
- your arthritis has not responded to intensive therapy with a combination of conventional DMARDs.

Usually tocilizumab is prescribed in combination with methotrexate, but it can be used on its own if you're unable to take methotrexate.

### In giant cell arteritis

Tocilizumab may be used to treat giant cell arteritis in adults if used with steroids that are gradually decreased. It can also be used by itself after steroids have been stopped. However, this is only the case if:

- you have a condition that has not responded to steroids by themselves, or has relapsed after having treatment with steroids
- you have not already received tocilizumab for your giant cell arteritis.

Tocilizumab should not be continued for more than one year in people with giant cell arteritis.

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

## Alcohol

There's no particular reason to avoid alcohol while taking tocilizumab. However, the government guidelines say that both men and women should drink no more than 14 units of alcohol a week, and that you should spread these through the week rather than having them all in one go.



You can find out more about units of alcohol at [www.drinkaware.co.uk](http://www.drinkaware.co.uk)

### Vaccinations

It's usually recommended that people on tocilizumab avoid the following live vaccines:

- yellow fever
- varicella-zoster (varry-sell-er zos-ter)
- typhoid
- rotavirus
- MMR (measles, mumps and rubella)
- BCG.

However, sometimes a live vaccine may be necessary, such as rubella immunisation in women of childbearing age. The annual flu vaccine is also recommended if you're taking tocilizumab.

If possible, all vaccinations for children should be brought up to date before beginning treatment. Do not have any vaccinations during your treatment without talking to your doctor.

### Shingles and chickenpox (Herpes zoster)

If you're offered a shingles vaccination, it's best if you can have this at least 14 days before starting tocilizumab.

Shingles vaccination isn't recommended for people whilst receiving tocilizumab.

People over 50 should have the shingles vaccination, unless there is a good reason not to. Shingles vaccination isn't recommended for children on tocilizumab.

### Pneumococcal and flu vaccines

Pneumococcal (new-mow-cock-all) vaccine, which protects against the most common cause of pneumonia, and yearly flu vaccines are safe and recommended. It is recommended that all patients receiving biologic therapies continue to have a yearly flu vaccination.

### Having an operation

If you take tocilizumab intravenously, it should be stopped at least four weeks before surgery. If you take tocilizumab subcutaneously (by injection or injection pen), it should be stopped at least two weeks before surgery.

Speak to your healthcare team for more details.

### Fertility, pregnancy and breastfeeding

It is recommended that you stop taking tocilizumab three months before conceiving. It's recommended that you use contraception while taking this drug, and for three months after stopping treatment.

It is not recommended that you take tocilizumab during pregnancy. However, if you unintentionally take it during the first three months of your pregnancy, it is unlikely to cause harm to your baby.

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 it.

There hasn't been any research into the effects of men taking tocilizumab while trying to conceive. However, it is unlikely to be harmful.

### Thank you!

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We would also like to give a special thank you to the people who shared their stories, opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.

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