

Tocilizumab

[arthritis-uk.org](https://www.arthritis-uk.org)

Tocilizumab is a drug used to treat rheumatoid arthritis, JIA, giant cell arteritis, Takayasu arteritis and adult-onset Still's disease

We are Arthritis UK

We're the 10 million adults, young people and children living with arthritis. We're the carers, researchers and healthcare professionals. The families and the friends. All united by one powerful vision: a future free from arthritis. So that one day, no one will have to live with the physical, emotional and practical challenges that arthritis brings.

There are many different types of arthritis. And we understand that every day is different. What's more, what works for one person may not help another. That's why our trusted information blends the latest research and expert advice with a range of lived experiences. In this way, we aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so that you can make better-informed choices to suit your needs.

We're always happy to hear from you whether it's with feedback on our information, to share your story, or just to find out more about the work of Arthritis UK. **Contact us at healthinfo@arthritis-uk.org**

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Introduction

Tocilizumab 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 healthcare professionals before you start treatment, so you're able to make an informed decision.

What is tocilizumab?

Tocilizumab is a biological therapy.

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.

If tocilizumab works for you, you'll probably start to feel the benefit in three to six months, depending on your condition. Some people 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.

Who can take tocilizumab?

You may be prescribed tocilizumab for:

- rheumatoid arthritis
- juvenile idiopathic arthritis (JIA)
- giant cell arteritis
- Takayasu arteritis
- adult-onset Still's disease.

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.

Tocilizumab is usually prescribed in combination with methotrexate. But it can be given on its own if you're unable to take methotrexate.

Tocilizumab can be taken for giant cell arteritis if your condition hasn't responded to steroids by themselves or has come back after having treatment with steroids. It may be used in combination with gradually decreasing steroid treatment, or by itself after steroid treatment.

You'll probably stop your treatment after a year. But your doctor or healthcare team will discuss this with you first.

You won't be given tocilizumab if:

- your arthritis isn't active
- you have a severe infection.

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, a condition caused by small pouches in the intestine
- you have certain heart problems
- you're pregnant or breastfeeding.

Before starting tocilizumab, you'll have blood tests to check your liver, kidney function and blood counts.

You'll have a chest X-ray and tests to check if you've ever been exposed to tuberculosis (TB). You may need treatment for TB before starting tocilizumab if it's in your body but isn't causing any symptoms.

You'll also be checked for HIV infection, and hepatitis B and C infections, as tocilizumab may increase the risk of these conditions starting up again or getting worse.

Tocilizumab can increase your cholesterol levels. You'll need blood tests before starting tocilizumab, and then every four weeks while taking tocilizumab.

You'll have regular tests while taking tocilizumab to monitor its effects.

How is tocilizumab taken?

	Rheumatoid arthritis	Giant cell arteritis	Systemic JIA	Polyarticular JIA
Subcutaneous injection: this is into the abdomen, thigh or upper arm	Once a week	Once a week	Once a week or once every two weeks, depending on body weight	Every two or three weeks, depending on body weight
Intravenous infusion: this takes about an hour	Every four weeks	This is not approved	Every two weeks	Every four weeks

An intravenous infusion is when the drug is given through a drip into a vein.

A subcutaneous 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 doctor or healthcare team.

If you have a latex allergy, you should mention this to your doctor. The needle cover on some pre-filled syringes may contain latex and could cause a reaction.

Because it's a long-term treatment, unless your doctor or healthcare team says otherwise, 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.

If you miss a dose or take one too soon, ask your doctor or healthcare team for advice on when to take your next dose.

Side effects and risks

The most common side effects are:

- a cough or sore throat, blocked or runny nose
- headaches, dizziness, or shortness of breath
- feeling sick
- sores in your mouth, known as mouth ulcers
- high blood pressure
- increased cholesterol in the blood
- bleeding
- allergic reactions – this can include aching muscles, feeling out of breath, having a tight chest, wheezing, and a high temperature
- putting on weight
- swollen ankles
- skin rashes, infections or itching
- tummy pain or constipation
- muscle weakness or cramps
- having difficulty sleeping.

In rare cases, you may have an allergic reaction. This could be in the form of swelling, a rash or you may feel short of breath. Contact your doctor or healthcare team if you think this may be happening. If the reaction is very bad, it's important you see your GP or go to your nearest Accident and Emergency (A&E) department as soon as possible.

You may feel dizzy while taking tocilizumab. This could affect your ability to drive and operate machinery. Tocilizumab has been shown to increase the risk of infections in patients with rheumatoid arthritis. It's important that any infections are treated as soon as possible.

You should see your doctor if you develop chickenpox or shingles, or if you come into contact with someone who has developed these illnesses. These illnesses can be worse if you're on tocilizumab. You may need treatment, and you might have to stop taking the drug until you're better.

Because tocilizumab affects the immune system, it can make you more likely to pick up infections.

Tell your doctor or healthcare team straight away if you develop any signs of an infection. They may also recommend that you temporarily stop tocilizumab if you're taking antibiotics.

Tips to reduce your risk of infection

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you're a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

Carrying an alert card

It's recommended that you carry a biological therapy alert card, so that anyone treating you will know you're on tocilizumab.

Ask your healthcare team for a card.

Taking other treatments

Tocilizumab may be prescribed along with other drugs, including methotrexate and steroids. Check with your doctor before starting any new medicines.

Remember to mention you're on tocilizumab if you're treated by anyone other than your usual rheumatology team, as it won't appear on your repeat prescription list from your GP.

You can carry on taking non-steroidal anti-inflammatory drugs (NSAIDs) or painkillers unless your doctor advises otherwise. Before using complementary treatments, such as herbal remedies, discuss it with your doctor, pharmacist or specialist, as some could interact with tocilizumab.

Vaccinations

It's best to discuss vaccinations with your doctor or healthcare team before starting tocilizumab.

It's very important that you have the pneumonia vaccine and yearly injectable flu vaccines to reduce your risk of infection. These vaccines are not live, so it's safe for you to have them.

It's recommended that you have the COVID-19 vaccination, if it's available to you.

You should avoid having live vaccines, such as MMR (Measles, mumps and rubella), yellow fever and rotavirus vaccines.

If you've never had chickenpox, it can be good to be vaccinated against it before starting tocilizumab. But discuss this with your healthcare team first.

The shingles vaccine, Shingrix, is a non-live vaccine. It's recommended that you have it if you're taking tocilizumab.

Having an operation or dental procedure

If you're having surgery or a dental procedure, talk to your surgeon or healthcare team.

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

Alcohol

There's no particular reason to avoid alcohol while taking tocilizumab.

UK guidelines recommend drinking no more than 14 units of alcohol a week. You shouldn't save these units to drink all at once, so try to spread your units across the week and have some alcohol-free days.

You should avoid alcohol if taking tocilizumab alongside methotrexate.



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

Fertility, pregnancy and breastfeeding

If you're planning to try for a baby, if you become pregnant or if you're thinking of breastfeeding, talk to your doctor or healthcare team.

Tocilizumab should be avoided during pregnancy, unless essential, as it's not yet known how the drug can affect an unborn baby.

If you've taken tocilizumab in the early stages of a pregnancy, it's unlikely to be harmful.

It should be fine to breastfeed while taking tocilizumab, but the research is limited so it would be a good idea to talk to your doctor about this.

There's currently no evidence that men need to stop.



This booklet is a guide to tocilizumab, its benefits and potential side effects. If there's anything else you'd like to know about this drug, speak to the healthcare professionals in charge of your care.

Discover our support services

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