

Ophthalmology department

Tocilizumab for steroid resistant thyroid eye disease (TED)

Information for patients, relatives and carers

Introduction

This leaflet aims to give you information about using tocilizumab (also called RoActemra®) to treat thyroid eye disease (TED). We hope this helps answer some of your questions. However, it's not meant to replace a talk with your medical team. If you have any questions about the information below, please contact us, using the contact details at the end of this leaflet.

Tocilizumab and thyroid eye disease

Tocilizumab is a treatment that helps the immune system. It does this by blocking proteins related to infections and inflammation. In particular, it blocks a protein called interleukin-6 (IL-6). There's often a lot of IL-6 present in inflammatory conditions.

Thyroid eye disease (TED) is when the immune system attacks healthy cells in the eye socket. It usually happens to people with an overactive thyroid gland. TED symptoms can include:

- red eyes
- dry, gritty or watery eyes
- puffiness
- painful swelling around the eyes
- the eyes are pushed forward in the eye sockets (become prominent). This is called proptosis

Rarer symptoms include:

- double vision
- poor vision

Treatment varies for each person. A course of steroid treatment is usually the first treatment if you have:

- lots of pain
- eyelid swelling
- double vision or vision problems

(please see leaflet on Immunosuppression for thyroid eye disease).

If the steroid treatment does not improve your symptoms enough, therapies like tocilizumab may be an option. This is called a second-line treatment.

Scientific evidence suggests tocilizumab is an effective and safe second-line treatment for patients whose disease did not respond to steroids. A group of clinical eye experts (the European Group on Graves' orbitopathy) also recommend it as a treatment for TED.

The use of medicines in the UK is approved (licenced) by the Medicines and Healthcare products Regulatory Agency (MHRA). The MHRA has approved the use of tocilizumab to treat inflammatory conditions like rheumatoid arthritis and giant cell arthritis. It has not yet approved tocilizumab to treat TED.

You can talk to the medical team about whether tocilizumab is the best treatment for you.

Do I need tests before starting tocilizumab?

Before starting tocilizumab, your medical team will need to perform several blood tests. If you have had blood tests before starting steroids, you may need some extra tests to ensure it is safe to proceed with the treatment.

How long does it take for tocilizumab to work?

Tocilizumab might not work straight away. It may take some months before you see any improvement. This is why it's important to come to your treatment appointments. Having the treatment at the right time will give you the most benefit.

Tocilizumab may not reduce the pushing forwards of the eyes (proptosis).

How will tocilizumab be given to me?

- you're given tocilizumab via a drip into a vein. This is an intravenous **infusion**
- you'll have an infusion once every 4 weeks
- your doctor will prescribe the right dose for you, based on your weight
- you will come into hospital for the day to have your treatment

Can I carry on taking my other medications?

Keep taking any treatment you usually have for your overactive or underactive thyroid condition. **This is very important.**

Tell your medical team about all the medications you are taking. This includes those you've bought over the counter, without a prescription. This is important as medicines can interact with each other.

So, bring a list of your current medications when you visit the doctor, nurse or pharmacist.

What should I do if I miss an infusion?

Tell your healthcare provider as soon as possible if you miss your infusion. This is important. They may be able to give you an infusion if it is less than a week after the scheduled date. Then you can have your next infusion on the planned date.

Everyone forgets appointments sometimes. But you need to have your infusion every 4 weeks to get the best out of it. So, plan how you will stick to the schedule. Put reminders in your phone, diary or calendar. Ask a friend or family member to remind you too.

How will you monitor my treatment?

You need to have regular blood tests while on tocilizumab treatment. This is because it can:

- cause high cholesterol
- affect your immune system
- affect the blood's ability form blood clots
- be damaging to the liver.

Regular blood tests will monitor for these potential side effects after you start tocilizumab. Your doctor will arrange the blood tests.

What are the side effects of tocilizumab?

Tocilizumab may cause side effects. This is like most medicines. Some people do not get any side effects. Possible common side effects include:

- increased risk of infection (cough, sore throat, runny nose)
- allergic reactions
- headaches
- dizziness
- abdominal pain
- feeling sick, diarrhoea, upset tummy
- raised blood pressure
- weight gain or swollen legs
- skin reaction

These side effects are expected to be felt by between 1 in 10 and 1 in 100 people who have tocilizumab. That means that between 9 in 10 people and 99 in 100 people will **not have side effects**.

When is it important to seek medical help?

Infections

Tocilizumab affects your immune system. This may make it harder for your body to fight infections. So, if you think you have an infection, it is **important to contact your doctor straight away**.

Digestive system

Tocilizumab can cause serious damage to the digestive system or gastrointestinal tract. This is uncommon and may affect 1 in 100 patients. So, it is important to seek urgent medical attention if you have:

- very bad pain in your tummy (abdomen) that does not go away
- high temperature (fever). This is usually 38C or above
- change in your pooing habits. You may be going more often or less often. Your poo might be different to normal

Liver damage

Tocilizumab can cause liver damage. Abnormal liver tests may be seen in every 1 in 10 patients. Tocilizumab, may rarely (1 in 1000 patients) cause inflammation of the liver. There is a 1 in 10,000 risk of liver failure. We will use your regular blood tests to look out for this.

But seek medical attention straight away if you notice:

- tummy pain (abdominal pain)
- feeling sick or being sick
- a lack of appetite
- dark-coloured pee
- light-coloured poo
- your skin looks yellow

Dizziness

Tocilizumab can cause dizziness. This may affect how well you can drive or perform skilled tasks. Take extra care until you know how tocilizumab affects you.

Do not drive or operate heavy machinery if you feel dizzy.

Vaccinations

If you are already taking tocilizumab, tell your doctor before having any vaccines. This is important.

It is safer to avoid certain vaccines while taking tocilizumab. These include vaccines against yellow fever, typhoid, rotavirus, MMR and BCG, and some shingles vaccines.

Your doctor can talk to you about other vaccines if needed.

Pregnancy, contraception and breastfeeding

Tell your medical team if you think you might be pregnant, family planning or breastfeeding.

We do not have much information about the use of tocilizumab in pregnancy. So, we advise pregnant people not to have tocilizumab treatment, unless essential.

We also need to be cautious about using tocilizumab while someone is breastfeeding. We do not know for certain if tocilizumab passes into breast milk or if it affects babies.

If it is possible for you to get pregnant, use effective contraception during treatment and for 3 months after.

Who can I contact for more information?

If you have any concerns or further questions, please:

- call us on 020 3312 9738
- email us at imperial.wehoutpatients@nhs.net

One of the doctors will get back you to discuss your concerns.

How do I make a comment about my visit?

Our team like to know when you're pleased with your care. So please contact us if you want to leave feedback.

We aim to provide the best possible service. Staff will be happy to answer any questions. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). Email PALS at imperial.pals@nhs.net

The PALS team will listen to your concerns, suggestions or queries. They can often help solve problems on your behalf.

Or you can **complain** by contacting our complaints department: Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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