



Patient Information – adnexal service

Intravenous steroid treatment for Thyroid Eye disease

This leaflet has been written for patients who may start intravenous (IV) steroid treatment for Thyroid Eye Disease. It aims to answer some questions you may have and serve as a reference throughout your treatment.

What is Thyroid Eye Disease?

Thyroid Eye disease (TED) is an autoimmune condition which affects the soft tissues, such as fat and muscle, that surround the eyes. The disease usually involves a period of swelling and inflammation, called the active phase, followed by some healing, called the inactive phase. TED occurs when the immune system mistakenly attacks its own tissues, producing autoantibodies that target the thyroid gland but also affect the eye tissues:

Some of the problems that can occur because of TED include:

- Puffy and red eyelids.
- Bulging of the eyes, due to swelling of the muscles and fat surrounding the eyes.
- Lid retraction, leading to dry eyes.
- Double vision.
- Painful eye orbits, especially on eye movement.

In some patients, the pressure around the eyes can increase due to inflammation which can compress the optic nerve, causing sight problems as the optic nerve transmits messages from the eye to the brain.

This information can be made available in alternative formats, such as easy read, large print, or alternative languages, on request. Please call PALS: 020 7566 2324/ 020 7566 2325.

What is intravenous steroid treatment?

Steroids can reduce inflammation and swelling around the eyes, relieving pressure on the optic nerves and preventing further eye damage. They can also alleviate pain and double vision caused by inflamed eye muscles.

However, they do not reverse any changes, such as bulging eyes and retracted eyelids, that have already been caused by the disease.

When you attend for your consultation at the eye clinic, the doctor will ask you some questions to gain a detailed clinical history. Based on this, they may recommend you take intravenous steroids. You may be required to take some additional tests before treatment is started.

What does the treatment involve?

The intravenous steroid treatment will be carried out in the eye clinic. You will see the doctor, who will explain the process of taking intravenous steroids, and the potential side-effects. You will then be taken to a consultation room where the nurse will take your blood pressure, pulse rate, breathing rate and blood sugar levels (if you have diabetes).

A small plastic tube, called a cannula, will then be inserted into the back of your hand. The intravenous steroid treatment will then be given through a saline drip. The treatment will take approximately one hour. At the end of the treatment, the cannula will be removed, and a small dressing will be applied. You will be able to go home after the treatment. You will receive one infusion every week, for 12 weeks

What are the side effects of treatment?

Steroids are powerful drugs, and so some patients can experience side-effects. The side-effects can vary significantly between people, and not everyone experiences side-effects. In the short term, the side-effects can be mild, and will usually resolve once you finish the treatment course.

The common side-effects include:

- A metallic taste
- Difficulty sleeping
- Indigestion
- Mood swings



- Increased appetite
- Flushing of the face (redness)
- Palpitations
- Headache

Long-term treatments can cause further side-effects:

- Weight gain
- Skin thinning
- High blood sugar
- High blood pressure
- Thinning of the bones (Osteoporosis)
- Cataracts

All patients will be started on a tablet to protect the stomach and a high dose of Vitamin D for the duration of the steroid treatment. Post-menopausal women and individuals over 50 may need a bone scan to assess the risk of osteoporosis.

If you have diabetes, steroid treatment may impact your blood sugar control. It is important to inform your diabetes doctor or nurse about your methylprednisolone treatment so they can adjust your medication if necessary. We also recommend monitoring your blood sugar more frequently during the steroid treatment.

Additionally, steroids can sometimes reveal underlying mental health issues. If you experience low mood during your treatment, especially if you feel you might be at risk of harming yourself, please seek help immediately from either our clinic, your GP practice or local Emergency Department. The NHS has freely available information online which can be accessed here: <u>Get help with low mood, sadness or depression - NHS (www.nhs.uk).</u>

If you suffer deterioration in your vision and/or colour vision, please contact 020 7253 3411 or attend the Moorfields Emergency department at City Road, open 24 hours a day, 7 days a week for eye emergencies only.

If you are worried or have any questions about the side effects of intravenous steroid treatment, please contact your ophthalmologist, who will be happy to discuss them with you.

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Moorfields Eye Hospital NHS Foundation Trust City Road, London EC1V 2PD Phone: 020 7253 3411 www.moorfields.nhs.uk

Moorfields Direct telephone helpline

Phone: 020 7566 2345

Monday-Friday, 8.30am-9pm

Saturday, 9am-5pm

Information and advice on eye conditions and treatments from experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)

Phone: 020 7566 2324 or 020 7566 2325

Email: moorfields.pals@nhs.net

Opening hours: Monday to Friday, except bank holidays

Moorfields' PALS team provides confidential advice and support to help you with any concerns you may have about the care we provide, guiding you through the different services available at Moorfields. The PALS team can also advise you on how to make a complaint.

Your right to treatment within 18 weeks

Under the NHS constitution, all patients have the right to begin consultant-led treatment within 18 weeks of being referred by their GP. Moorfields is committed to fulfilling this right. For more information about your rights and responsibilities, please visit the Moorfields website and search 'Referrals to treatment (RTT)'. To learn more about your rights under the NHS constitution, visit www.nhs.uk/choiceinthenhs

