

Ophthalmology department

Immunosuppression for thyroid eye disease (TED)

Information for patients, relatives and carers

Introduction

This leaflet has been designed to give you information about immunosuppression for Thyroid Eye Disease (TED), and answer some of the questions that you or those who care for you may have. It is not meant to replace the discussion between you and your medical team but aims to help you understand more about what is discussed. If you have any questions about the information below, please contact the ophthalmology department using the numbers on page 7.

What is thyroid eye disease?

Thyroid eye disease (TED) is an autoimmune inflammatory disorder affecting the tissues within the eye socket. Symptoms include pain, swelling, redness, watering, retraction of the upper eyelids, conjunctivitis, bulging eyes, double vision and, occasionally, decreased vision.

We recognize that TED is a distressing, disfiguring and sometimes vision-threatening condition that causes a significant decrease in quality of life. Therefore, we believe patients should be cared for by both endocrinologists (doctors who treat diseases related to problems with hormone) and ophthalmologists (eye doctors) to optimize your care.

If you experience intense pain, increased double vision, decreased vision or loss of colour vision at any point in your treatment please call the Western Eye Hospital's emergency department for an urgent review.

Treatment for TED

It is very important to regulate your thyroid hormone levels and, if you're a smoker, to stop smoking. Most patients are advised to take Selenium supplements 200mcg once a day for 6 months and to continue with lubricating eye drops.

You have been recommended to start on immunosuppression treatment for TED due to the significant level of inflammation in your eye socket(s), which is causing pain and/or double vision.

Your treatment plan will consist of a:

- 12-week course of intravenous steroids, and
- 24-week course of oral Cellcept (Mycophenolate Mofetil MMF).

We will carry out some blood tests and a chest x-ray to make sure it is safe for you to start the treatment.

Your 12-week course of intravenous steroid treatment

Steroids are powerful drugs and need to be given in a hospital setting via a vein in your hand (intravenously). This will involve being admitted to hospital for 1 day (known as a day case). Intravenous steroids are preferred rather than oral steroid tablets because they are more effective in treating TED and have fewer side effects. Steroids do not reverse the disfigurement (bulging eyes and retracted eyelids) caused by the disease but they are effective in controlling pain and improving symptoms of double vision that are caused by the inflamed eye muscles in many cases.

The treatment consists of one infusion given weekly over 12 weeks. We will be able to answer any questions about the risks and side effects of the intravenous steroid treatment before starting it.

If your vision is badly affected because of the TED, a more intense course of steroids may be given more regularly. We will discuss this with you.

During the treatment you will usually need to be monitored by the thyroid multidisciplinary team (MDT) at monthly intervals. If you experience double vision, you will need separate appointment(s) with an orthoptist who is a specialist practitioner who measures eye movements. Usually this will take place before/soon after starting your steroid treatment so that we have baseline measurements to monitor your progress against during the treatment.

Other possible side effects of the steroids

Not everyone experiences side effects when taking steroids but some people do. In the short-term, the side effects are usually mild and will go away soon after you finish the treatment course.

The most common side effects include a metallic taste, indigestion, difficulty sleeping, mood swings or altered mood and flushing of the face (redness), increased appetite, headache, palpitations (faster than normal heart rate), rash and swelling of the ankles. It is also important to check for signs of infection as steroids can make infections worse.

Allergic reactions are very rare but you will be monitored in the day unit while receiving the steroid infusion.

Long-term treatment with steroids can lead to further potential side effects such as weight gain, diabetes, skin thinning, cataracts and osteoporosis (thinning of the bones). We therefore try to avoid giving more than one course of steroid therapy.

For all patients, we will also start a high dose of vitamin D for the duration of your steroid treatment. If you are over the age of 50 or post-menopausal, we will be assessing your individual risk of osteoporosis and will arrange a bone scan if necessary.

You will be regularly monitored during your course of treatment and we are happy to answer any questions you have about the risks and possible side effects.

Your 24-week course of oral Cellcept (Mycophenolate Mofetil (MMF) treatment

Mycophenolate is sometimes prescribed under the names mycophenolate mofetil or mycophenolate sodium and has a number of uses. It stops the eyes from becoming inflamed again while reducing the risk of causing damage to your eyes when you stop the steroid treatment. The aim is to carry on the MMF treatment for a further 12 weeks after stopping the steroids (24 weeks in total) although some patients may need longer or other treatments.

Mycophenolate slows down how active your condition is, rather than just treating how its symptoms affect you. It works by reducing the activity of your body's immune system.

When your immune system is working properly, it protects you by fighting off infection and illness. But in inflammatory conditions, your immune system may attack parts of your body by mistake, such as your eyes.

Other uses

As well as TED, mycophenolate is used to treat:

- connective tissue disorders (e.g. lupus, scleroderma, rheumatoid arthritis, psoriatic arthritis)
- uveitis (inflammation of the middle layer of the eye, called the uvea or uveal tract)
- conditions in which there's inflammation of blood vessels, such as vasculitis
- inflammatory conditions affecting the bowel, such as Crohn's disease
- after organ transplantation it helps stop the immune system rejecting the new organ

Please note that mycophenolate doesn't work immediately and it may take up to four months before you notice any benefit.

When and how do I take mycophenolate?

Mycophenolate is usually given as a capsule or as a tablet, depending on the dose you need. It is also manufactured as an injectable infusion and an oral solution.

You shouldn't crush or chew mycophenolate - you should always swallow them whole. It's recommended that you take the capsule or tablet with food and water, as this can stop you feeling sick and getting stomach pains. Your doctor or pharmacist will advise you about the correct dose.

It's important to keep taking mycophenolate even if it doesn't seem to be working at first. It's also important to keep taking it when your symptoms start to improve, as this will help control your condition.

Side effects and risks

Mycophenolate can cause a number of side effects, including:

- feeling sick
- diarrhoea
- vomiting
- stomach pains

While you're taking mycophenolate, tell your doctor or pharmacist straight away if you start experiencing any new symptoms or anything that concerns you. Let them know immediately if you have:

- a sore throat
- a fever
- flu-like symptoms
- a constant cough or problems breathing
- the sensation that your heart is beating unusually
- sudden weight loss
- unexplained bruising or bleeding
- unexplained changes in mood
- headaches – particularly if you don't usually get them
- acne or a skin rash
- swollen gums or an unusual taste in your mouth

If any of these symptoms are severe, your doctor may advise you to stop taking mycophenolate. It's always best to talk to your doctor before making any changes to your treatment.

You should also see your doctor as soon as possible if you come into contact with anyone with shingles or chickenpox, or if you get them yourself. You may need antiviral treatment and your mycophenolate may be stopped until you're better.

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 with you
- keep your mouth clean by brushing your teeth regularly

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- 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

Other complications

Although it's rare, there's a slightly increased risk of certain types of cancer, such as skin cancer, in people using mycophenolate. However, the link between the two is unclear.

Skin cancers can often be treated successfully when diagnosed early. To be on the safe side, make sure to wear sunscreen and regularly check your skin for any new spots or changes to your freckles or moles.

Very rarely, patients treated with mycophenolate can develop a serious condition called progressive multifocal leukoencephalopathy, which is also known as PML, which can damage the brain and spinal cord. You must see your doctor immediately if you notice any of the following symptoms:

- pins and needles
- weakness, shaky movements or unsteadiness
- sight loss
- speech problems
- changes in behaviour or mood
- difficulty moving your face, arms or legs

Mycophenolate can affect the blood count and can sometimes cause liver or kidney problems. As a precaution, your doctor will arrange for you to have a blood test before you start treatment and regular blood tests while you're taking mycophenolate.

Frequently asked questions?

What if I miss a dose of mycophenolate?

Take your missed dose as soon as you remember, unless it's almost time for your next one. If you have missed a tablet, don't take any more than your regular dose to make up for it.

What if I take too much mycophenolate?

If you take too much of your medication you may experience some of the side effects mentioned on page 4.

If you think you have taken too much mycophenolate call your endocrinology team or the NHS helpline on 111 immediately and ask for advice. You can also contact the NHS helpline team through their website at 111.nhs.uk

Can I take other medicines at the same time as mycophenolate?

Mycophenolate may be prescribed along with other drugs to treat your condition. But some drugs can interact with mycophenolate.

Before you start any new medication it's always a good idea to talk to your doctor first to make sure the treatments are okay to take together.

You can carry on taking non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, or painkillers, if needed, unless your doctor advises otherwise.

However, you shouldn't take over-the-counter preparations or herbal remedies without first discussing them with your doctor or pharmacist.

You should tell any other healthcare professionals treating you such as doctors, pharmacists, dentists or nurses that you're taking mycophenolate.

Can I have any vaccinations?

If you're taking mycophenolate, you should avoid live vaccines, such as yellow fever. However, in certain situations a live vaccine may be necessary, so speak to your pharmacist or doctor about this for advice.

It's a good idea to get the pneumococcal vaccine, to protect you against the most common cause of pneumonia, and your yearly flu vaccines. These are both safe to have while you're being treated with mycophenolate.

Covid-19 vaccine: You can have the Covid vaccine by any manufacturer (Pfizer, AstraZeneca, etc.). Please tell your treating team about it before having the vaccine as mycophenolate has to be stopped 1 week before and 1 week after the vaccination.

What if I am due to have surgery?

If you're going to have an operation, discuss this with your doctor. They will tell you whether you should continue taking your mycophenolate before your operation.

Can I drink alcohol?

Mycophenolate and alcohol can both affect your liver, so you should only drink alcohol in small amounts. Government guidelines say both men and women should have no more than 14 units of alcohol a week, and that you should spread these throughout the week rather than having them all in one go (Drinkaware.co.uk).

Advice can vary and some doctors may suggest stricter limits. If you're concerned you should discuss your alcohol intake with your endocrinology team.

How about fertility, pregnancy and breastfeeding?

You shouldn't take mycophenolate while you're trying for a baby, pregnant or breastfeeding. It does not affect your fertility but it can affect your unborn child.

Your doctor may discuss your future plans for a family before prescribing mycophenolate. Whether you're a man or woman, you'll be advised to use one, if not two, methods of contraception while you're being treated with mycophenolate.

If you want to try for a baby, you should talk to your doctor first before you stop using contraception.

Women are advised to wait 6 weeks after stopping treatment before trying to conceive. Men are advised to wait 13 weeks before they stop using contraception. This allows the drug to fully leave your system.

If you're taking mycophenolate and you think you or your partner may be pregnant, contact your doctor immediately, they will be able to advise you on the best course of action.

If there's a possibility you may be pregnant, take a pregnancy test before starting mycophenolate.

You shouldn't breastfeed if you're on mycophenolate, as the drug may pass into your breast milk which could harm your baby.

Who can I contact for more information?

- Emergency department at the Western Eye Hospital: **020 3312 3245**
- Outpatients at the Western Eye Hospital: **020 3312 3236**
- Outpatients at Charing Cross Hospital: **020 3311 1109/ 1233/ 0137**

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. 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) . You can also email PALS at imperial.pals@nhs.net

Alternatively, you may wish to 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

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