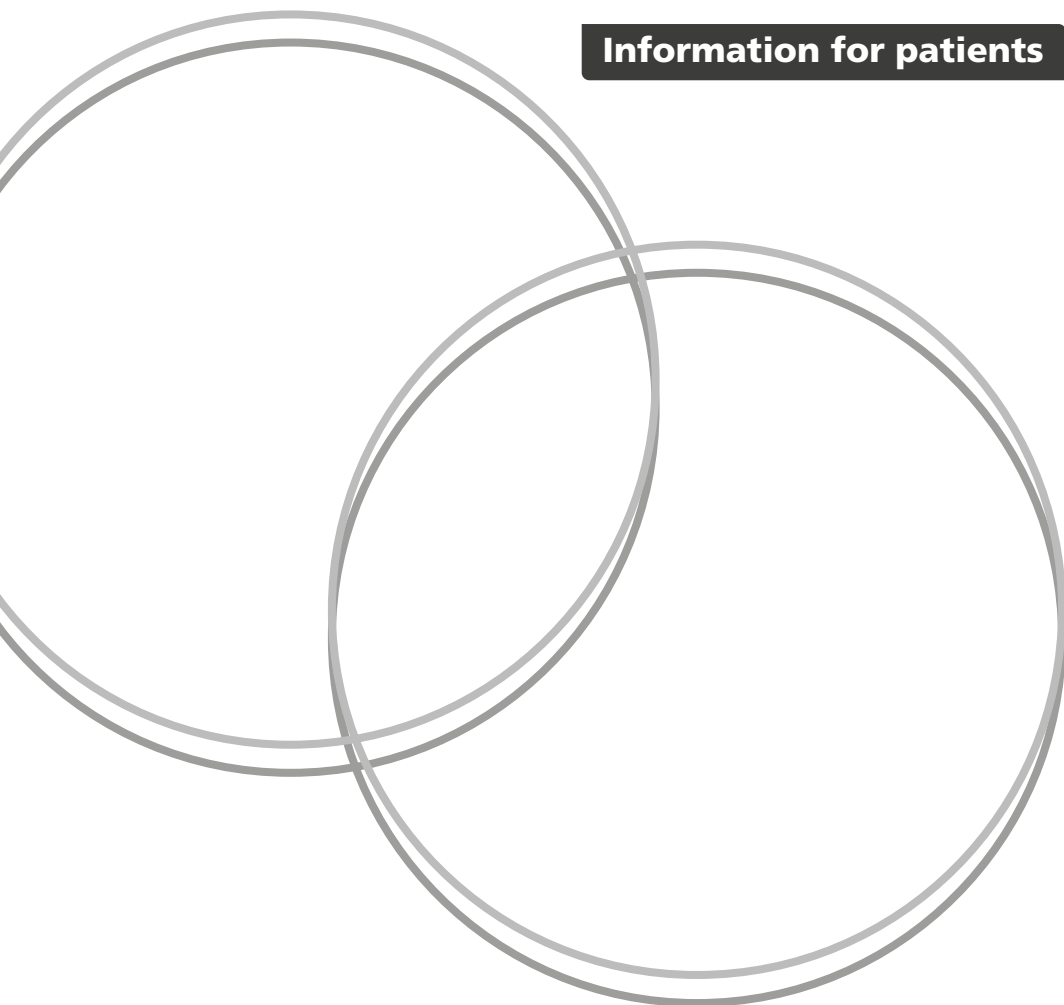


Oral Mycophenolate Mofetil

**For patients with
Thyroid Eye Disease**

Information for patients



This leaflet explains:

- What thyroid eye disease is
- What mycophenolate mofetil is and why it is used
- How long it takes to work
- Blood tests and monitoring
- Possible side effects
- Pregnancy and fertility advice
- Who to contact for help

What is thyroid eye disease?

Thyroid eye disease (TED) happens when the immune system causes inflammation and swelling around the eyes.

Symptoms can include:

- Eye pain or pressure
- Red or swollen eyes
- Bulging eyes
- Double vision
- Changes in appearance
- Problems with eyesight (in severe cases)

TED often occurs in people with Graves' disease (an overactive thyroid), but it can also happen when thyroid levels are normal or low.

What is mycophenolate mofetil?

Mycophenolate mofetil (CellCept) is a medicine that reduces the activity of the immune system.

It is taken as a tablet by mouth.

In thyroid eye disease, mycophenolate mofetil helps to:

- Reduce swelling and inflammation around the eyes
- Improve pain, redness and discomfort
- Help protect your eyesight

How long does mycophenolate mofetil take to work?

Mycophenolate mofetil does not work straight away.

- Some improvement may be noticed after 3 to 6 months
- The full effect is usually seen after 6 to 12 months

Most patients improve, but a small number may not respond. If mycophenolate mofetil is not suitable for you, your team will discuss other treatment options.

Blood tests and monitoring

Regular blood tests are needed to make sure the medicine is safe for you.

Weekly blood tests for the first 4 weeks

Tests check:

- Blood cell levels
- Liver function
- Kidney function
- Signs of infection

If results are normal, blood tests will be less frequent. Your healthcare team will tell you how often you need them.

What improvement can I expect?

Many people notice:

- Less eye pain and pressure
- Reduced swelling
- Better comfort
- Improvement in vision

Steroids often work quickly, but results vary between people.

Possible side effects

Like all medicines, mycophenolate mofetil can cause side effects, although not everyone gets them.

Common side effects (these are usually mild):

- Headache
- Shaking or tremor
- Stomach upset or indigestion
- Skin rash
- Dizziness
- Difficulty sleeping
- Hair thinning or hair loss
- Reduced appetite

Less common but more serious side effects

- Mycophenolate mofetil can reduce blood cell counts. This may cause:
 - Easy bruising
 - Increased risk of infections

This is why regular blood tests are important.

Treatment is usually for between 6 – 18 months. Therefore, risks such as neurotoxicity and skin cancer are unlikely.

Pregnancy and contraception

Mycophenolate mofetil can seriously harm an unborn baby.

- Do not take Mycophenolate mofetil if you are pregnant
- Avoid pregnancy while taking mycophenolate mofetil
- You must avoid pregnancy for 6 months after stopping the medicine
- Male patients or their female partner should use effective contraception during treatment and for 90 days after discontinuation.

Tell your healthcare team IMMEDIATELY if you are:

- Pregnant
- Planning a pregnancy
- Not using reliable contraception

Your team can discuss safe options with you.

When should I seek help?

Contact us or seek medical help urgently if you develop:

- A fever or signs of infection
- Breathing problems
- Sudden changes in your vision

Please DO NOT come to the Oxford Eye Hospital straight away.

Call our specialist telephone triage number:

Tel: **01865 234 567**

and select the option for 'eye emergencies'.

Monday to Friday 8:30am - 4:30pm

Saturday and Sunday 8.30am – 3.30pm (including Bank Holidays)

You will be able to speak to an ophthalmic health professional who will advise you.

If you need advice out of hours, please phone NHS 111 or your out of hours GP practice.

For less urgent issues contact the Ophthalmology Secretaries:

Tel: **01865 234567**

Email: OculoPlastics@ouh.nhs.uk

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

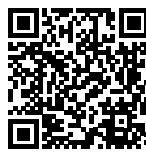
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