



## Mycophenolate Mofetil for uveitis

### What is Mycophenolate Mofetil?

Mycophenolate Mofetil (MMF) is an immunomodulatory drug. It is commonly used to prevent organ rejection in transplant patients and to treat autoimmune diseases. MMF is also prescribed to reduce inflammation of the eyes and protect vision in autoimmune conditions such as uveitis and thyroid eye disease.

### Mycophenolate Mofetil and uveitis

Uveitis is an inflammation of the uvea, the middle layer of the eye, which can lead to vision loss if untreated. MMF has been shown to be effective in managing ocular inflammation linked to uveitis. Studies show that approximately half of the patients treated with MMF experience significant improvement in their condition.

### Mycophenolate Mofetil and thyroid eye disease

Thyroid eye disease is a condition in which the eye muscles, eyelids, tear glands and fatty tissues behind the eye become inflamed. Alongside treatment with intravenous (IV) steroids, studies have shown that MMF is effective in treating moderate to severe thyroid eye disease and protecting vision.

### How to take Mycophenolate Mofetil?

- **Dosage:** Take MMF exactly as prescribed by your doctor, usually twice a day. In uveitis, the most commonly prescribed dose is 1g twice a day. Your doctor may start you on a low dose to monitor for side effects and adjust the dosage as needed. If you have been prescribed MMF for thyroid eye disease, then you will be prescribed a dose of 500mg twice a day for six months.
- **Administration:** Swallow the tablets whole with a glass of water, preferably with food to reduce stomach upset. Do not crush or chew them.
- **Consistency:** Take your doses at the same time each day to maintain a steady level of the medication in your body.
- **Missed dose:** If you miss a dose, take it as soon as you remember. If it is almost time for your next dose, skip the missed one - do not take two doses at once.
- **Storage:** Keep MMF at room temperature and away from moisture or heat.

### How long will it take for it to start working?

MMF can take up to 12 weeks to take effect and improve uveitis symptoms. To help control inflammation while waiting for MMF to take effect, your doctor may also prescribe steroids, which work quickly. Once MMF has had enough time to start working, your doctor will gradually reduce the steroid dose. It is important to keep taking MMF as prescribed and attend all follow-up appointments with your eye specialist.

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## What are the possible side effects?

Like all medications, MMF can cause side effects, but these vary from person to person. Side effects are more likely to happen during the first six weeks as your doctor gradually increases the dose.

### Very common side effects:

- **Stomach and gut issues:** You may experience nausea, diarrhoea, vomiting, or stomach pain. If these symptoms are bothering you, your doctor may adjust your dose or switch you to a similar medication that may be gentler on your stomach.
- **Increased risk of infection:** MMF affects your immune system, making you more prone to infections.
- **Blood changes:** This medication can lower the number of certain blood cells, which may lead to anaemia (causing tiredness and breathlessness) or increase the risk of bruising and infections.

### Less common side effects:

- **High blood pressure and cholesterol:** Some people develop raised blood pressure or cholesterol levels, which your doctor may monitor with regular blood tests.
- **Mood changes:** Low mood or feelings of depression have been reported by some people taking MMF. If this happens, speak to your doctor.
- **Hair loss:** Some patients notice hair thinning or hair loss while on MMF. This is usually mild but can be distressing.

### Rare but serious side effects:

- **Severe infections:** Because MMF weakens your immune system, you are at a small risk of more serious infections, such as pneumonia. Seek urgent medical advice if you develop a high fever, persistent cough, or you feel very unwell.
- **Unexplained bruising or bleeding:** This may be a sign of a problem with your blood cells. Contact your doctor if you notice this.
- **Risk of skin cancer:** There is a slightly increased risk of skin cancer. Avoid exposure to strong sunlight, protect your skin with sunblock/sunscreen with SPF 30+ and above and regularly check your skin for any new spots or changes to your freckles or moles. Please avoid using sunbeds.
- **Progressive Multifocal Leukoencephalopathy (PML):** this is a rare complication which can damage your brain and spinal cord. Please inform us if you notice symptoms such as pins and needles, shaky or unsteady movements, sight loss, speech problems, changes in behaviour or mood, or difficulty moving your face, arms and legs.

To help monitor for these side effects, your doctor will arrange regular blood tests. If you experience any new or worrying symptoms, speak to your doctor or pharmacist.

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## Interactions with other treatments

Some medications and supplements can interfere with MMF, so it is important to let your doctor know about everything you are taking.

- **Avoid Non-Steroidal Anti-Inflammatory Drugs (NSAIDs):** Painkillers like ibuprofen and naproxen can increase the risk of side effects when taken with MMF. Speak to your doctor before using any pain relief.
- **Be cautious with herbal remedies:** Some herbal supplements including Chinese herbal remedies can affect how MMF works or increase the risk of side effects. Always check with your doctor before taking any herbal or over-the-counter treatments.
- **Medication review:** Your doctor will review all your regular medications to check if they could interact with MMF and cause side effects.

## Fertility, pregnancy and breastfeeding

- **Pregnancy:** MMF should not be used during pregnancy because it is known to cause birth defects and premature birth. If there is a chance you could become pregnant, you are advised to use effective contraception during treatment and for 12 weeks after stopping. Men are advised to use contraception during treatment and for at least 90 days after stopping MMF.
- **Breastfeeding:** It is not recommended to breastfeed while taking MMF, as the drug can pass into breast milk and may harm the infant.

## Vaccinations

While taking MMF, your immune system is weaker, which means some vaccines may not work as well, and **live vaccines** should be avoided. Live vaccines contain weakened viruses that could cause infection in people with suppressed immune systems. **Live vaccines to avoid include:**

- Measles, Mumps, and Rubella (MMR)
- Varicella (Chickenpox)
- Shingles (Zoster)
- Yellow Fever
- Oral Polio Vaccine
- Bacillus Calmette-Guérin (BCG) for tuberculosis
- Live Influenza (nasal spray)
- Rotavirus

Before getting any vaccine, speak with your doctor to ensure it is safe for you. Inactivated (non-live) vaccines such as the flu, COVID-19, pneumonia and Shingrix (non-live Shingles vaccine) are usually safe and recommended.

## Preventing infections

Since MMF weakens the immune system, it is important to take extra precautions to reduce your risk of infections:

- **Avoid close contact with sick people** especially those with colds, flu, or other contagious illnesses.

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- **Wash your hands regularly** with soap and water or use hand sanitizer when soap is not available.
  - **Keep your environment clean**, including frequently touched surfaces like phones, keyboards, and door handles. Keep your bathroom, toilet and kitchen surfaces clean.
  - **Practice food hygiene** - avoid undercooked meat, unpasteurised milk and raw seafood. If you eat out at restaurants and use takeaways, ensure that they practise good hygiene.
  - **Wear a mask in crowded places** if there is a high risk of infection.
  - **Viral infections** - If you come into contact with anyone who has a viral infection like chicken pox, please see your GP. You will be prescribed anti-viral treatment as a precaution. Please pause taking MMF while you are taking the anti-viral medication.
  - **COVID-19** - If you test positive for COVID-19, then you are eligible for COVID-19 antibody treatment. This treatment is only effective when given within five days of testing positive. The best way to access treatment is to contact 111 and follow their advice. Please pause taking MMF while you are receiving the antibody treatment.
  - **Antibiotics** – If you are prescribed antibiotics by your GP or other health care professionals to treat infections, you may have to pause taking MMF for the duration of the antibiotic course. Please seek advice from the health care professional prescribing the medication or contact us for advice. Pausing MMF can give your immune system a chance to fight the infection and for the antibiotics to take effect.
  - **Seek medical advice if you develop a fever, persistent cough, or any signs of infection.**

## Screening, monitoring and follow-up

Prior to starting treatment with MMF, you will have blood tests to check if the drug is suitable for you and that you do not have an active infection. This will ensure safety of your health and the effectiveness of the drug. You will have had most of the tests done at your initial appointment.

Regular follow-up appointments are important to monitor your response to MMF and adjust dosages if necessary. Blood tests will be performed regularly to check for side effects and ensure the medication is working effectively.

Blood tests will generally include a full blood count, kidney and liver function tests. The frequency of the tests is fortnightly for the first six weeks, then monthly for the next three months and then every 3 months. These tests can be arranged at the eye clinic or with your local GP surgery or hospital.

Generally, you will be prescribed three month's supply of MMF. Please inform us via the contact details provided at the end of this leaflet when you have two weeks of medication left so we can prescribe the medication without any delay. We cannot prescribe MMF without a recent blood test. So please ensure you have regular blood tests for your safety.

You will be on the treatment for a minimum of two years or more depending on how stable the inflammation in your eyes is. If you have surgery or infections, then based on the type of surgery or severity of the infection, the medication may be paused temporarily. Therefore, please inform us if you have any planned surgery or catch an infection.

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## Available support and resources

<https://versusarthritis.org/about-arthritis/treatments/drugs/mycophenolate>

<https://www.rnib.org.uk/your-eyes/eye-conditions-az/uveitis/>

<https://www.rnib.org.uk/sightline-directory/organisations/queen-elizabeth-hospital-birmingham-eclo-service-c616b0ec-4bec-4784-a65a-74898751d700/>

## Department contact information: weekdays excluding bank holidays

**Uveitis email address:** [uveitis@uhb.nhs.uk](mailto:uveitis@uhb.nhs.uk) (08:00 – 17:00)

**Jacqui Orpe, secretary:** 0121 371 6905 (Monday, Tuesday, Friday)

**Carolyn Rivera, specialist nurse:** 07823 827040 (08:00 – 17:00, Monday, Tuesday, Thursday, Friday)

**Hermey Skew, specialist nurse:** 07388 711893 (08:00 – 17:00, Tuesday, Wednesday, Thursday, Friday)

**Gurmeet Kaur, specialist nurse (only for patients with thyroid eye disease):** 07468760298, 08:00 – 16:00, Monday to Friday

**Main ophthalmology outpatient clinic:** 0121 371 6476, 0121 371 6477 (08:00 – 18:00, Monday to Friday)

**Appointments Team:** 0121 371 6925, 0121 371 6787 (08:00 – 16:00, Monday to Friday)

**Hospital Pharmacy:** 0121 371 5479, 0121 371 5480

**Homecare pharmacy (deliveries):** 0121 371 3933

**Out of hours:** we do not provide an out of hours service.

In cases of emergency such as:

- sudden drop in vision
- sudden appearance of or increase in floaters (dots floating across your field of vision)
- flashing lights
- redness in the eye with severe pain and sensitivity to light
- appearance of a shadow or curtain across your vision with a drop in vision

please contact or visit your local eye casualty.

If you are a Birmingham resident, your local eye casualty is BMEC (Birmingham Midland Eye Centre). Please note that the average wait time can range from 2 hours to 6 hours.

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**Address:** City Hospital, Dudley Rd, Birmingham B18 7QH.

**Phone number:** 0121 5076779

**Opening hours:**

8.30am – 7pm, Monday to Friday

9am – 7pm – Saturday

9am – 6pm – Sunday

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