

Ophthalmology department

# Using mycophenolate mofetil to treat your uveitis

## Information for patients, relatives and carers

### Introduction

This leaflet provides information about using mycophenolate mofetil (also called Cellcept® or Myfortic®) to treat uveitis. Mycophenolate mofetil can help stop uveitis causing damage to your eye. You also need to discuss this 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.

### What is mycophenolate?

Sometimes the body's defence system attacks its own cells. This is called an autoimmune condition. Mycophenolate is one of the medicines used to treat autoimmune conditions. It is an immunosuppressant.

### How mycophenolate helps treat uveitis

Autoimmune conditions can cause uveitis. But sometimes we cannot find a specific cause.

Uveitis causes inflammation and damage to the eye. This can threaten your sight. It can lead to permanent damage to the eye.

**Mycophenolate** helps reduce the inflammation. It can help slow down or stop permanent damage. It does this by lowering your immune system activity.

You need to take mycophenolate regularly. You might not notice a difference for several weeks. But it's important to give it time to work.

Unfortunately, mycophenolate does not work for everyone.

### How soon will I notice a difference with my symptoms?

Mycophenolate does not work straight away. It can take up to 4 months before your symptoms improve.

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## How do I take mycophenolate?

- Your doctor will prescribe the right dose for you. They will change the dose if needed
- you usually take it twice a day as a tablet or capsule
  - swallow the tablets or capsules whole with a mouthful of water
  - do not crush or break the tablets or capsules

Keep taking mycophenolate, even if it feels like it is not helping. It can take a few weeks or months to notice the effects.

## Can I continue taking my other medications?

Bring a list of all your medicines when you visit the doctor, nurse or pharmacist. Tell them about all the medicines you are taking. Include medicines or supplements you've bought without a prescription. **This is important because medicines can affect each other.**

Avoid taking:

- antacids if they contain magnesium or aluminium. (These medicines help with indigestion and heartburn)
- iron supplements

## What should I do if I miss a dose of mycophenolate?

Take your missed dose as soon as you remember, unless it is almost time for your next one. **Do not** take more than your regular dose to make up for the missed dose.

## Will I need blood tests during my treatment?

Mycophenolate can affect your blood count. It can sometimes cause kidney or liver problems. So, before starting treatment, we will carry out an initial blood test. You'll then need regular blood tests to monitor your blood count, kidney and liver function.

## Does the treatment affect pregnancy, contraception and breastfeeding?

**Do not take mycophenolate if:**

- you are or might be pregnant
- are trying to start a family
- are breastfeeding

This is because there is a potential risk to the developing pregnancy. Mycophenolate can cause babies to have birth abnormalities. It can also cause miscarriages.

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**Tell your doctor immediately if:**

- you think you might be pregnant
- are planning a family

**If it is possible for you to get pregnant and you are taking mycophenolate:**

- **contraception or birth control:** you must use two reliable types of contraception at the same time during treatment. You need to keep using them for 6 weeks after treatment ends
- **pregnancy tests:** you'll need to take a pregnancy test 8 to 10 days before treatment begins. You'll have another test right before starting. More pregnancy tests are recommended during treatment. For example, if you miss a dose of contraception
- **breastfeeding:** mycophenolate passes into breastmilk. So, please tell your doctor if you are breastfeeding

**If you are a man taking mycophenolate:**

We suggest you and your partner use reliable contraception or birth control during treatment. Continue this for at least 90 days after treatment ends. There is no clear evidence that a father taking mycophenolate increases the risk of birth abnormalities or miscarriage. But it cannot be ruled out. Men should not donate sperm during treatment and for 3 months after. If you think you or your partner might be pregnant, talk to your doctor immediately

**Do not stop taking mycophenolate without speaking to your doctor first.**

## Will I be more at risk of viral infections?

Mycophenolate lowers your immune system. This reduces your body's ability to fight infections. As a result, you may be more likely to get an infection of your:

- skin
- mouth
- stomach and intestines
- lungs
- urinary tract

Tell your doctor if you have symptoms of infection that last more than 3 days. These could be a sore throat, fever or cough.

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## I've never had chickenpox, does this matter?

Tell your doctor or nurse straight away if you get close to someone who has chickenpox or shingles. You can have a bad reaction to these infections if you are taking mycophenolate.

## What else do I need to be aware of during my treatment?

### Monitor alcohol intake

Drink no more than 14 units of alcohol per week, spread evenly over 3 or more days.

### Check about vaccinations

Ask your doctor or pharmacist for advice before getting vaccinations while taking mycophenolate. We advise you avoid certain vaccines. These include live vaccines against yellow fever, typhoid, rotavirus, MMR and BCG, and some shingles vaccines.

### Limit sun exposure

Mycophenolate can make your skin more sensitive to real and artificial or UV light. This includes sunbeds. So, limit your exposure. Protect your head, neck, arms and legs from the sun. Use protective clothing and sunscreen with a high protection factor like SPF 50.

### Avoid infections

- try to avoid close contact with people who have active infections
- try to avoid bacterial infections from food. Store and prepare your food safely

### Pause blood donation

- if you're a blood donor, do not donate blood during treatment or for 6 weeks after

## What are possible side effects of mycophenolate?

Mycophenolate can cause side effects. This is the same as most medicines. Most people will not get side effects.

Possible common side effects, which affect between 1 in 10 and 1 in 100 people, include:

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| • headaches and dizziness                       | • continuous cough or breathing problems     |
| • feeling sick                                  | • acne, hair loss, rash and joint pain       |
| • stomach pains                                 | • unexplained changes in mood                |
| • diarrhoea or being sick (vomiting), or both   | • unexplained bruising or bleeding (anaemia) |
| • constipation                                  |  |
| • increased infection risk (fever, sore throat) |  |

Possible rare side effects, which affect less than 1 in 10,000 people, include:

- bleeding, bruising or a rash
- change in the colour and amount of your pee
- long-lasting, unusual changes in behaviour

If you have these, **stop** taking mycophenolate. Seek urgent medical advice.

## 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](mailto:imperial.wehoutpatients@nhs.net)

One of the uveitis 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](mailto: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](mailto: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](mailto:imperial.communications@nhs.net)

## Wi-fi

Wi-fi is available at our Trust. For more information visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)