

# Mycophenolate Mofetil

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## Information for patients and carers from the Haematology Department

### Why have I been prescribed Mycophenolate?

You have been prescribed Mycophenolate as you have immune thrombocytopenia (ITP) or autoimmune haemolytic anaemia. These are disorders where your body's immune system attacks your healthy cells.

Although Mycophenolate is not licensed for these disorders, there is good evidence to support that it can help to treat them.

### How does Mycophenolate work?

Mycophenolate reduces the activity of the immune system. It is often used instead of steroids, which can have long term side effects.

Mycophenolate usually takes longer to work than steroids and may take several weeks before it starts to take effect.

### How do I take it?

Mycophenolate comes as either tablets or capsules and is available in two different strengths - 250mg and 500mg. You should take it with or soon after food. The tablets or capsules should be swallowed whole. Do not break or crush them, as it is not safe to breathe in the powder.

Once you have been prescribed and started taking Mycophenolate do not stop taking it unless instructed by your doctor, as you need to continue taking it to keep control of your condition.

### What happens if I forget to take a dose?

If more than six hours has passed from the usual time you take your dose, then miss that dose and take the next dose at the normal time. Do not double the dose.

If you take too much Mycophenolate, please speak to your GP for advice.



### **What are the possible side effects?**

The most common side effects of Mycophenolate are nausea (feeling sick), vomiting, and diarrhoea. Taking your daily amount in divided doses throughout the day can reduce these symptoms. For example, if your daily dose is 1000mg, you could take four doses of 250mg throughout the day.

Any side effects that you have should improve after a few weeks of taking the medication.

As Mycophenolate suppresses your immune system, this can cause anaemia, make you more likely to develop infections, and tend to bruise easily.

Occasionally, Mycophenolate may cause abdominal pain. This is caused by inflammation of the liver or pancreas, which can lead to increased blood sugar levels.

As with any drug that affects the immune system, there is a small increased risk of developing lymphoma (cancer of the lymphatic system) or skin cancer. If you take this medication you will need to limit your exposure to sunlight and UV light, by wearing clothing that covers exposed skin and using high factor sunscreen.

Other reported side effects include allergic reactions, high temperature, tiredness, headache, difficulty sleeping, hair loss, a rash, and changes to blood pressure.

### **What should I do if I experience any side effects?**

If you experience any signs of infection, such as a high temperature above 37.5°C, a sore throat, or cough, you should contact your GP or pharmacist immediately. Tell them your symptoms and that you are taking Mycophenolate.

You should also seek medical attention if you develop side effects such as unexplained bruising, bleeding, shortness of breath, excessive tiredness, yellowing of your skin or the whites of your eyes, or severe itching (these are signs of liver damage).

If you come into close contact with anyone who has chickenpox or shingles, and you have not previously had these conditions, please tell your GP as soon as possible.

### **What monitoring is needed while taking Mycophenolate?**

You will need regular blood tests to check your blood cell counts and liver function, whilst you are taking this medication. This will need to be done at least every week for the first four weeks, then monthly, and then at two to three monthly intervals. You will be told whether the blood tests will be carried out at the Haematology Clinic or at your local GP surgery.

### **Will Mycophenolate interfere with my other medicines?**

Before you start any new medicines, you must check with your doctor or pharmacist whether they might interact with Mycophenolate, especially those drugs and treatments that are not prescribed by a doctor (such as over the counter medication or herbal remedies).

It is safe to drink alcohol in moderation whilst on Mycophenolate, but this may make any diarrhoea and nausea you may have worse.

### Should I still have vaccinations?

Seasonal vaccinations against influenza are recommended for people of any age whilst they are taking Mycophenolate, as well as vaccination with the pneumococcal polysaccharide vaccine against pneumonia. Mycophenolate does not appear to increase the risk of catching influenza, but the illness can be more severe whilst taking this medication.

You should avoid having 'live' vaccinations, such as polio, MMR, and the shingles vaccine.

### What about using contraception or getting pregnant?

The use of Mycophenolate in pregnancy has been linked with birth defects and pregnancy loss, so it should not be used in pregnancy or if you are planning to get pregnant. If you become pregnant whilst taking Mycophenolate, contact your GP or haematologist immediately.

Before starting Mycophenolate, if you are female and aged between 15 and 45, you will need to have two negative pregnancy tests, carried out eight to 10 days apart. These tests may be either urine or blood tests and will be arranged at the hospital.

You should use two effective methods of contraception (for example the contraceptive pill and barrier methods, such as condoms) during treatment with Mycophenolate and for six weeks after stopping treatment.

If you are male, or have male partners, and are taking this medication you should use condoms (even if you have had a vasectomy). You should do this for at least 90 days after stopping treatment, as it can affect your sperm. If you have a female partner, they should also use effective contraception whilst you are being treated, and for 90 days after your last dose of the medication.

### Can I breastfeed while taking Mycophenolate?

No. If you are breastfeeding you should not take Mycophenolate.

### Where can I find more information?

For more information, the best person to speak to is your doctor (haematologist or GP).

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

**Any complaints, comments, concerns, or compliments** please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email [ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)

**Patients should not bring in large sums of money or valuables into hospital.** Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

**Further patient leaflets** are available via the East Kent Hospitals web site [www.ekhuft.nhs.uk/patientinformation](http://www.ekhuft.nhs.uk/patientinformation)