



The Leeds  
Teaching Hospitals  
NHS Trust

# Mycophenolate Mofetil

## Treatment of Autoimmune liver disease

Information for  
patients

This leaflet contains information about Mycophenolate to treat Autoimmune Hepatitis (AIH). This leaflet will give you more information about this medication.

If you need to get in touch with one of the team nurses, please use the contact details below:

Liver Secretaries:

Tel: **0113 2064856**

Clinical Nurse Specialists:

Tel: **0113 2069275**

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Liver Pharmacy Team:

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## Dose of Mycophenolate Mofetil

Date commenced	Dose

## Blood test monitoring

Blood tests are required regularly whilst taking mycophenolate. Initially, this is every 2 weeks for the first 2 months and then monthly for 4 months. Once you are on a stable dose, you will need bloods every 3 months.

You can use the box below to record the dates you need to attend for bloods.

	Date
<i>Week 0</i>	
<i>Week 2</i>	
<i>Week 4</i>	
<i>Week 6</i>	
<i>Week 8</i>	
<i>Month 1</i>	
<i>Month 2</i>	
<i>Month 3</i>	
<i>Month 4</i>	

**This leaflet contains information about Mycophenolate Mofetil to treat autoimmune hepatitis.**

### **Why have I been given this leaflet?**

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with the treatment.

For most medicines, information is provided by the manufacturer in the medicine package. This leaflet aims to provide more specific information regarding mycophenolate for your liver condition than the manufacturer's patient information leaflet found in your box of mycophenolate.

### **So this medicine does not have a licence. What does this mean?**

The leaflet called Unlicensed Medicines: Information for Patients tells you more about medicine licensing regulations.

It also tells you why unlicensed medicines are sometimes used.

### **Why does Mycophenolate Mofetil not have a licence?**

Sometimes, a medicine has been licensed for a certain use and later use shows that it works for a different illness.

The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money so sometimes the manufacturer decides it is not worth their while. Mycophenolate Mofetil is made by the manufacturer for transplant patients to prevent organ rejection; however, it is also widely used in the treatment of autoimmune hepatitis. Remember that your doctor will have thought carefully about which medicine is best for your condition.

## **What is Mycophenolate Mofetil and how does it work?**

Your blood contains both white and red blood cells. The white cells in the blood form part of the immune system and these can cause damage to the liver. Mycophenolate helps to reduce the effectiveness of the white blood cells and is used to try to reduce the inflammation and scarring they cause in the liver.

## **How should I take Mycophenolate Mofetil?**

Mycophenolate Mofetil is available as a tablet, capsule or suspension. Tablets and capsules should be swallowed whole, do not crush or chew.

Ideally, take mycophenolate on an empty stomach.

## **Mycophenolate Pregnancy and Breastfeeding and Contraception Advice**

Mycophenolate carries some risks related to pregnancy and breastfeeding.

### **For women:**

- you will need a pregnancy test before taking this medication if you are sexually active;
- you must use effective contraception (birth control) whilst taking Mycophenolate Mofetil and for at least 6 weeks after your last dose. If you have sex with a man, use two reliable forms of contraception at the same time; and
- talk to your doctor immediately if you think you could be pregnant. Do not stop Mycophenolate Mofetil until you have spoken to your doctor.

### **For men (including those who have had a vasectomy):**

- Male patients or their untreated female partner must use reliable contraception during mycophenolate treatment and for at least 90 days after stopping treatment; and
- talk to your doctor immediately if you think your partner could be pregnant and do not stop Mycophenolate Mofetil until you have spoken to your doctor.

### **For men and women:**

- tell your doctor if you are planning a pregnancy.

Do not take this medication if you have a hypersensitivity to Mycophenolate Mofetil or mycophenoloic acid.

- Do not donate blood whilst you are on Mycophenolate Mofetil and for at least 6 weeks after your last dose.

Take extra care on sunny days when there are high levels of UV and sunlight. Sunscreen with a high protective factor should be applied and protective clothing worn such as long sleeves and trousers.

**Please tell your doctor if you have any of the conditions listed above or in the manufacturer's leaflet.**

## **Do I need any special checks while on Mycophenolate Mofetil?**

Mycophenolate Mofetil reduces the production of blood cells making you more vulnerable to infections and can sometimes affect the liver. Blood tests will show if you are developing any side-effects. If you are being affected, your treatment will be changed or stopped immediately.

It is important that you do not miss your blood tests. You must not take Mycophenolate Mofetil unless you are having regular blood tests. When you start Mycophenolate Mofetil, you will need a blood test every 2 weeks for 2 months, then monthly for 4 months and then every 3 months when your dose is stable. Your doctor may increase or decrease the number of tablets you take at each dose depending upon the results of your tests.

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## Are there any side-effects?

Most medicines cause side-effects. The manufacturer's leaflet contains a list of the known side-effects for this medicine.

Everyone reacts differently to medicines. You may have some side-effects or none at all. One of the most common side-effects with Mycophenolate Mofetil is diarrhoea. If this persists for more than a few days or becomes unbearable, you should contact your doctor. In some patients, Mycophenolate Mofetil can also cause a feeling of sickness, loss of appetite, hair loss and skin rashes.

If you have any of these effects, you do not need contact the doctor unless they persist for more than a few days or become unbearable.

There are some rare but serious side-effects that you would need to tell your doctor about immediately.

Taking Mycophenolate Mofetil can affect the blood count (one of the effects is that fewer blood cells are made). Your regular blood count test will check how well your bone marrow is working. Possible indicators of bone marrow damage are anaemia, regularly catching infections, and bruising and bleeding easily. Report any infection, unexpected bruising or bleeding to a healthcare professional.



**If you have any of the following, tell your doctor immediately.**

- Infections including fever, chills or a sore throat.
- Bleeding gums, black tarry stools, or unexpected bleeding or bruising.
- Severe and continuing diarrhoea, vomiting or stomach pains.

See your doctor if you develop any new symptoms after starting Mycophenolate Mofetil.

**Will Mycophenolate Mofetil affect any other medicines?**

Full information on medicines that can interfere with mycophenolate can be found in the manufacturer's patient information leaflet found in your box of mycophenolate.

If you take any of these medicines, tell your doctor or pharmacist and they will advise you.

Do not take iron supplements or antacids / indigestion remedies (e.g. Gaviscon®) within 2 hours of mycophenolate.

Tell your doctor or pharmacist about all the other medicines you take. This includes any medicines you have had prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

Whenever you are prescribed a new medicine or want to buy a medicine e.g. from a pharmacy or supermarket, it is important that you tell the doctor or pharmacist about all the medicines that you take, including Mycophenolate Mofetil. You should also tell your dentist when you see him / her.

## **Will Mycophenolate Mofetil affect any vaccinations?**

Live vaccinations such as yellow fever should be avoided in patients treated with Mycophenolate Mofetil. Non-live (inactivated) vaccinations may be less effective.

The pneumonia, flu and COVID vaccines are all safe and recommended.

If you need to have a vaccine while taking Mycophenolate mofetil, talk to your doctor first. They will be able to advise you on what vaccines you can have.

## **Can I drink alcohol while I am taking Mycophenolate Mofetil?**

Yes, it is safe to drink alcohol while you are taking Mycophenolate Mofetil; however, large quantities of alcohol should be avoided. It is recommended that you do not exceed the national guidelines.

## **Where should I store Mycophenolate Mofetil at home?**

Store Mycophenolate Mofetil in a cool, dry place away from direct sunlight.

**It is important that all medicines are stored out of reach of children.**

## **Where do I get my next supply?**

When you are on a steady dose of mycophenolate, your GP should take over the supply. Until then, this will be supplied from hospital.

You must make sure you get repeat prescriptions to your local pharmacy in good time. The pharmacy may not have the medicine in stock and may need a few days to arrange a supply.

## **How can I find out more?**

This leaflet has been written to provide general information about Mycophenolate Mofetil. If you have any further questions or concerns, please speak to your doctor or pharmacist.



## What did you think of your care?

Scan the QR code or visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)

*Your views matter*



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