

# Taking mycophenolate mofetil for your respiratory condition

Respiratory Medicine

Information for Patients

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## What are the aims of this leaflet?

This leaflet has been written to help you understand more about mycophenolate mofetil. It will tell you what it is, how it works and how it is used to treat interstitial lung disease (ILD). ILD covers a wide range of conditions which affect the lungs.

## What is mycophenolate mofetil and how does it work?

Mycophenolate mofetil (MMF) is a medicine that can be used to treat lung diseases and other conditions that cause inflammation in the body such as arthritis and to stop the body from rejecting transplanted organs. It is used in certain lung conditions where your immune system attacks your own body. Mycophenolate mofetil lowers the body's own defense system (the immune system) and is one of a group of drugs known as immunosuppressants. It aims to reduce the inflammation that may contribute to symptoms of breathlessness and cough.

## When should I take mycophenolate mofetil?

The dose is usually 2 times a day, and taken morning and evening. The medication should be swallowed whole (capsule/tablet, do not chew or crush).

## What dose of mycophenolate mofetil should I take?

Mycophenolate mofetil is available in 250 mg capsules and 500 mg tablets. It is also available as a liquid which can be used for people who are unable to swallow capsules or tablets.

**Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice**

Visit [www.leicestershospitals.nhs.uk](http://www.leicestershospitals.nhs.uk) for maps and information about visiting Leicester's Hospitals  
To give feedback about this information sheet, contact [InformationForPatients@uhl-tr.nhs.uk](mailto:InformationForPatients@uhl-tr.nhs.uk)

The normal dose is between 1 and 3 g daily. You should only take the dose advised by your ILD specialist team. You will usually start on a low dose and gradually increase the dose as advised by your ILD team.

Your recommended dose:

Starting Dose	_____ mg	_____ A DAY	_____ WEEKS
Increased dose	_____ mg	_____ A DAY	_____ WEEKS
Increased dose	_____ mg	_____ A DAY	_____ WEEKS
Increased dose	_____ mg	_____ A DAY	

## How long will I have to take mycophenolate mofetil for?

The length of treatment will depend on which lung disease you have and how well you respond to treatment. You may need to take mycophenolate mofetil for at least 3 months before you notice any change in your condition. If you find it works, mycophenolate mofetil can be taken long term. If you are also taking prednisolone (steroid), it may mean that your dose of prednisolone can be reduced by your ILD specialist.

## What are the possible side effects of mycophenolate mofetil?

Mycophenolate mofetil has been used for many years and most patients do not have any problems. Occasionally it can cause side effects. The most common side effects of mycophenolate mofetil are

- feeling sick (nausea),
- diarrhoea,
- or stomach pain.

Mycophenolate mofetil can also affect your blood count (fewer white blood cells are made) and make you more likely to get infections. You should tell your doctor or ILD specialist team straight away if you develop any of the following whilst taking mycophenolate mofetil :

- A sore throat
- A fever or chills
- Any other symptoms of infection
- Unexplained bruising or bleeding
- Any other new symptoms or anything else that concerns you

Patients on long-term mycophenolate mofetil are more likely than others to develop some forms of cancer including skin cancers and lymphoma. All patients should avoid too much exposure to

sunlight and use high factor sunscreen (SPF 50). Sunscreens are not an alternative to clothing and shade, rather they offer additional protection. Please be aware that no sunscreen will provide 100% protection. Tell your doctor about any changes to a mole or patch of skin.

## How can I reduce the risks?

You should stop your mycophenolate mofetil and see your doctor or contact your ILD specialist team immediately if:

- You have any of the symptoms in the list above, e.g. sore throat, and they are severe
- You develop chickenpox or shingles or come into contact with someone who has chickenpox and shingles and you haven't had chickenpox in the past. You may need treatment with antiviral medicine as chickenpox and shingles can be severe in people on immunosuppressants. Your mycophenolate mofetil will be stopped and only re-started when you feel better.

As mycophenolate mofetil affects your immune system it may make you more likely to pick up infections, you should avoid people who have recently been in hospital and if possible people with recent infections.

If you are being treated for any infection we advise you to stop the mycophenolate mofetil while you are on antibiotics and to restart it at your previous dose 1 week after stopping antibiotics (unless advised differently by your ILD team).

## How will I be monitored for the side effects of mycophenolate mofetil treatment?

Your ILD specialist team will arrange the first blood test. After this you need to go to your GP surgery or hospital for the tests. Blood tests are frequent at first, every 2 weeks but are needed less often (e.g. usually every 1 to 3 months) once you are set up on treatment. These checks monitor your full blood count, liver and kidney function. You may be asked to keep a record of your results in a booklet - you should bring this with you when you visit your GP or the hospital

You must have regular blood tests while taking mycophenolate mofetil.

## Contact details

Interstitial lung disease (ILD) team 0116 258 3949 8am to 4pm

**Space for notes/questions:**


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اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔  
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

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