Trusted Information Creator
Patient Information Forum

NHS
University Hospitals of Leicester
NHS Trust

Taking mycophenolate mofetil for interstitial lung disease

Respiratory Medicine
Information for Patients

Last reviewed: September 2026
Next review: September 2029
Leaflet number: 1236 Version: 2

Introduction

This leaflet explains more about your interstitial lung disease (ILD) and your medicine, mycophenolate mofetil. It covers:

- how the medicine works,
- how and when to take it,
- side effects to look out for,
- why you need regular blood tests,
- who to contact if you need help or another supply,

What is interstitial lung disease (ILD)?

Interstitial lung disease, or ILD, is the name for a group of lung conditions. These conditions can cause inflammation, scarring, or both. Inflammation and scarring can make the lungs stiff. This can make breathing more difficult and reduce the amount of oxygen that passes into your blood.

What is mycophenolate mofetil and how does it work?

Mycophenolate mofetil is often shortened to mycophenolate or MMF. It is an immunosuppressant. It reduces the activity of your immune system.

In some types of ILD, the immune system is overactive and causes inflammation in the lungs. Mycophenolate aims to reduce this inflammation. It may help to prevent or slow further lung damage. It cannot reverse scarring that has already formed.

Mycophenolate is licensed to prevent rejection after an organ transplant. It is not licensed specifically for ILD. However, there is clinical evidence and experience to support its use in some types of ILD. This is known as “off-label” use. Your ILD team can explain this in more detail.

Mycophenolate works slowly. It may take up to 3 months before you notice any benefit. You may not notice an improvement in your cough or breathlessness, even when the medicine is helping to control your ILD.

How should I take mycophenolate mofetil?

Mycophenolate mofetil is usually taken 2 times a day. You take it once in the morning and once in the evening. Swallow the tablets or capsules whole with water. Do not crush, break, chew or open them. It is also available as a liquid. This can be used for people who cannot swallow capsules or tablets.

The usual total dose is between 1g and 3g each day. Take only the dose prescribed by your ILD team.

Your ILD team will normally start you on a low dose. They will slowly increase the dose if your blood-test results are satisfactory and you are not having troublesome side effects.

Always follow the instructions from your ILD team. Your dose may be different from the example shown in the table.

Starting dose	500 mg	Once a day	2 weeks
Increased dose	500 mg	Morning and evening	2 Weeks
Increased dose	1000 mg 500 mg	Morning Evening	2 weeks
Increased dose	1000 mg	Morning and evening	Ongoing

What should I do if I miss a dose?

Take the missed dose when you remember. If it is nearly time for your next dose, leave out the missed dose and take your next dose at the usual time.

Do not take 2 doses together. Contact your ILD team or pharmacist if you are not sure what to do.

How long will I take mycophenolate?

This will depend on your type of ILD and how well the treatment works for you. It may take at least 3 months to assess its effect.

If the medicine helps and your blood-test results are good, you may take it long-term.

If you also take prednisolone, your ILD team may slowly reduce your prednisolone dose. Do not reduce or stop either medicine unless your healthcare team tells you to.

What are the possible side effects of mycophenolate mofetil?

Like all medicines, mycophenolate can cause side effects, although not everyone gets them.

Common side effects include:

- feeling sick (nausea) or being sick (vomiting),
- diarrhoea,
- stomach pain,

Contact your GP or ILD team right away if these symptoms are severe or do not settle.

When should I get urgent medical advice?

Contact your GP, NHS 111 or ILD team right away if you develop:

- a high temperature, fever or chills,
- a severe sore throat or mouth ulcers,
- signs of an infection,
- new or worsening cough or breathlessness,
- unexplained bruising or bleeding,
- a new rash, blisters or peeling skin,
- severe or persistent sickness or diarrhoea,
- unexpected weight loss,

Call 999 if you develop difficulty breathing or swelling of your face, lips, mouth or throat.

Chickenpox and shingles

Contact your GP or ILD team urgently if:

- you develop chickenpox or shingles,
- or you have close contact with someone who has chickenpox or shingles and you are not sure if you have previously had chickenpox.

These infections can be more serious while you are taking mycophenolate. You may need antiviral treatment. Your healthcare team will tell you whether to pause mycophenolate and when to restart it.

Contact your healthcare team if you develop another symptom that concerns you.

Protecting your skin

Mycophenolate may slightly increase the risk of some cancers, mainly skin cancer and lymphoma.

- Avoid strong sunlight and sunbeds.
- Stay in the shade when possible.
- Wear a hat and clothing that covers your skin.
- Use a high-protection sunscreen and reapply it regularly.

Contact your GP if you notice a new lump, a sore that does not heal, or a change in a mole or patch of skin.

What should I do if I have an infection?

Mycophenolate reduces the activity of your immune system. This can make infections more serious.

Keep taking mycophenolate if you have a minor illness, such as a mild cold, unless a healthcare professional tells you to do something different.

Contact your GP or ILD team right away if:

- you have a high temperature or feel very unwell,
- your infection is severe or is getting worse,
- your infection is not improving as expected,
- you have been prescribed antibiotics,
- you need hospital treatment,

Your healthcare team may tell you to pause mycophenolate during a serious infection. Do not stop or restart mycophenolate unless a healthcare professional has advised you to do so.

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

Mycophenolate can affect your blood cells, liver and kidneys. Regular blood tests help us find problems early. Your tests will check your full blood count, liver function and kidney function.

You will usually need a blood test:

- Every 2 weeks for the first 6 weeks.
- Every 4 weeks for the next 3 months.
- Every 3 months once your dose and results are stable.

You may need extra tests after a dose change or if a result is outside the expected range or if you are higher risk. Your ILD team will tell you if your monitoring schedule is different. You can have your blood tests at your GP surgery or at a Leicester hospital blood-test department. You must take your blood-test form with you. Contact the ILD team if you need more forms. It is important that you have your blood tests as your next prescription may be delayed if your monitoring is overdue.

How do I get more medication?

You will get your first 3-month supply from TrustMed Pharmacy at Glenfield Hospital.

To get your next supply, call TrustMed Pharmacy on **0116 235 5474**. Please request it at least 2 weeks before your medicine runs out.

Once your dose and blood-test results are stable, we may ask your GP to prescribe mycophenolate under a shared-care arrangement. We will let you know if this happens.

Can I take other medicines with mycophenolate mofetil?

Tell your doctor, pharmacist or ILD team about all the medicines you take. This includes medicines bought from a pharmacy, vitamins and herbal products.

Some medicines can affect how mycophenolate works. These include:

- indigestion remedies containing magnesium or aluminium,
- iron supplements,
- some medicines used to treat infections,
- some medicines that affect the immune system,

You may need to take some of these medicines at a different time from mycophenolate. Ask your pharmacist or ILD team for advice.

Do not start, stop or change another medicine without checking with a healthcare professional.

Pregnancy, contraception and breastfeeding?

Mycophenolate can cause miscarriage and serious birth defects. Do not take it during pregnancy unless a specialist has decided that there is no suitable alternative. Do not breastfeed while taking mycophenolate.

If you could become pregnant

- You will need a negative pregnancy test before starting treatment. A second test may also be needed.
- Use at least 1 reliable form of contraception during treatment and for 6 weeks after your last dose. Using 2 methods is preferred.
- Contact your ILD team before trying for a baby.
- If you think you may be pregnant, contact your ILD team immediately. Do not make treatment changes without urgent specialist advice.

If you could father a child
Either you or your female partner should use reliable contraception during treatment and for 90 days after your last dose. Speak to your ILD team before trying for a baby.

Do not donate blood during treatment or for 6 weeks after your last dose. Do not donate semen during treatment or for 90 days after your last dose.

Can I have vaccinations?

Check with your doctor, pharmacist or vaccination service before having a vaccine.

Do not have a live vaccine while taking mycophenolate unless your specialist team says it is safe. Live vaccines include MMR, yellow fever, the nasal flu vaccine and the live shingles vaccine.

The Shingrix vaccine is not a live vaccine. Injected flu, COVID-19 and pneumococcal vaccines are safe and **recommended**. However, they may not work as well while you are taking mycophenolate. Temporarily stopping mycophenolate for 2 weeks after your COVID-19 or flu vaccination can significantly improve your body's immune response.

Can I drink alcohol while taking mycophenolate mofetil?

You can drink alcohol while taking mycophenolate but keep within the recommended limit of no more than 14 units a week. If you drink as much as 14 units, spread this over 3 or more days.

Ask your healthcare team for advice if you have liver problems.

Where can I find out more about mycophenolate mofetil?

If you want to know more about mycophenolate mofetil or if you are worried about your treatment, you should speak to your ILD specialist team.

This leaflet does not list all the side effects and interactions of mycophenolate mofetil. Read the patient information leaflet that comes with your mycophenolate mofetil.

Contact details:

For all prescription requests and enquiries, please call TMP at Glenfield Hospital on **0116 235 5474**

Visit accurx.nhs.uk/patient-initiated/rweild or scan the QR code on the right to send a query to the ILD team.

Any concerns or changes to your symptoms or medication please contact the ILD team on **0116 259 3949**

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice
Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
إذا كنت ترغب في الحصول على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.

If you would like this information in another language or format such as EasyRead
or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

We are a research hospital and you may be asked to take part in research

Re-use of this leaflet is restricted by Creative Commons license