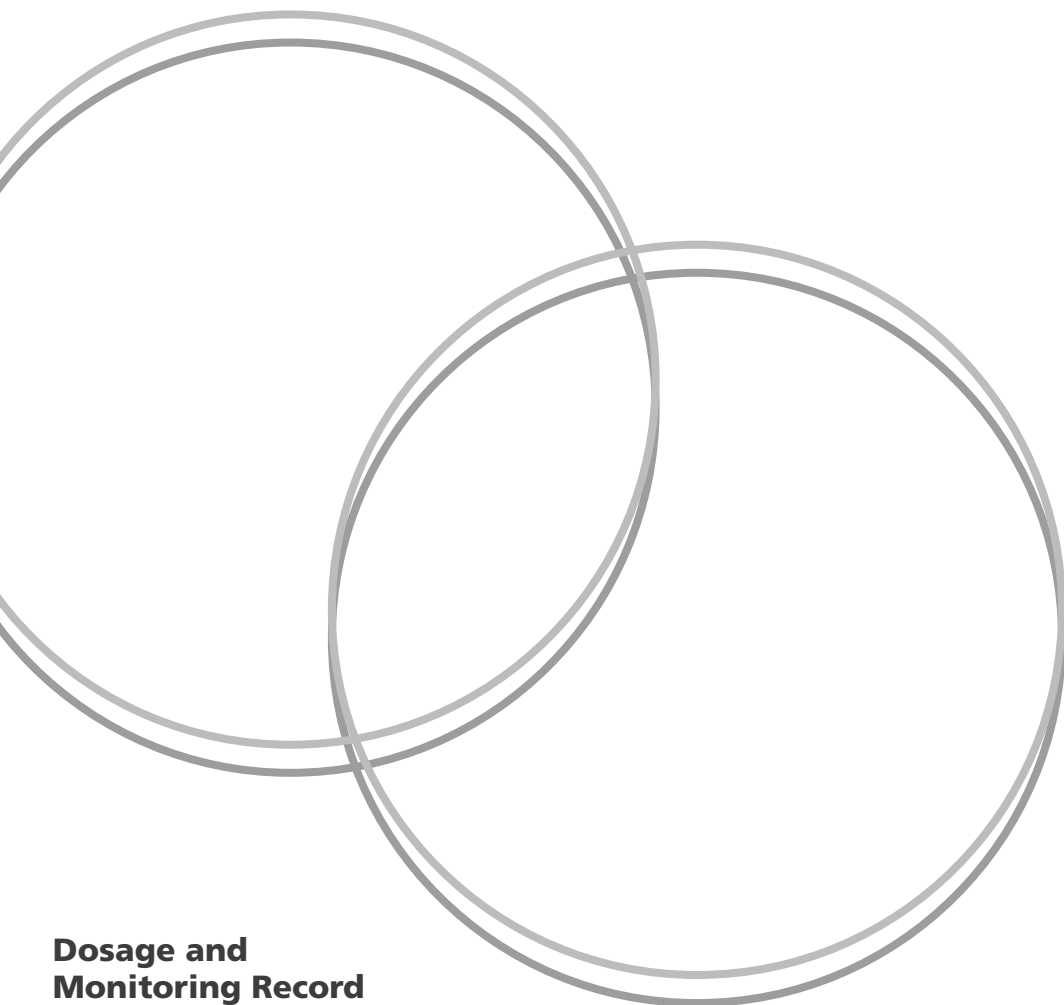


# Mycophenolate Mofetil for Interstitial Lung Disease

**Information for patients**



**Dosage and  
Monitoring Record**

## **Why have I been prescribed this medication?**

Mycophenolate Mofetil is an immunosuppressant medication. These are used to dampen down the body's immune system in conditions where the immune system is overactive and reacts against your own body.

With interstitial lung disease (ILD), mycophenolate is used to reduce inflammation, which can contribute to your symptoms of breathlessness and reduce your ability to exercise.

Although mycophenolate is not licensed for use for ILD, there is good evidence to support that it can help to treat it. Please ask for our leaflet 'Unlicensed and 'off-label' medicines', for more information.

## **How does it work?**

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

If you are already taking prednisolone, taking mycophenolate will usually mean that your dose of prednisolone can be reduced and possibly stopped.

Mycophenolate usually takes longer to work than steroids. It can take up to 8 to 12 weeks before you have any benefit. It is important to continue taking the mycophenolate during this time.

## How do I take it?

Mycophenolate Mofetil comes as either tablets or capsules and is available in two strengths – 250mg and 500mg.

You should take it with a glass of water, 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.

Do not stop taking the mycophenolate unless instructed by your doctor, as you need to take it to keep control of your lung condition.

### Recommended dose of Mycophenolate

Your doctor will decide the best dose for you to take, depending on your body weight.

The dose will usually start off low, to make sure you do not suffer from side effects.

If you have no negative effects from the medication, the dose will be increased by your doctor.

Your recommended dose:

Initial dose:	..... mg <b>ONCE a day</b>	Start date:
Increased dose:	..... mg in the Morning <b>and</b> ..... mg in the Evening	Start date:
Increased dose:	..... mg in the Morning <b>and</b> ..... mg in the Evening	Start date:
Maintenance dose:	..... mg in the Morning <b>and</b> ..... mg in the Evening	Start date:

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

If more than 6 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 up the dose.

If you take too much Mycophenolate Mofetil, please speak to your GP or contact the ILD nurses.

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

The most common side effects of mycophenolate are nausea, vomiting and diarrhoea. Taking half your total daily dose in the morning and half in the evening can reduce these symptoms (but do not split tablets/capsules in half).

As mycophenolate suppresses the immune system this can cause you to develop anaemia, be more likely to develop infections and more likely to bruise easily.

Occasionally mycophenolate may cause abdominal pain, due to inflammation of the liver or pancreas. This can cause an increase in blood marker levels.

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

Mycophenolate may cause hair loss or thinning. Hair growth usually returns to normal, even if treatment continues, but you should avoid hair dyes or perms for the first few months, as your hair will be weaker than normal.

This is not the full list of possible side effects; please refer to the information within the medicine packet for a complete list.

## **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, cough or mouth ulcers, you should contact your GP or ILD nurse immediately. Please tell them that you are taking Mycophenolate Mofetil.

You should also stop taking the medication and seek medical attention either from your GP or the Oxford ILD team if you develop side effects such as unexplained bruising, bleeding, shortness of breath, excessive tiredness, yellowing of your skin or whites of your eyes, or severe itching (signs of liver damage).

If any of the following symptoms develop, stop taking the mycophenolate and inform your GP and the ILD team immediately:

- redness of your skin or skin rash
- fever, shivering or chills
- feeling dizzy, confused, light-headed, weak or generally tired
- muscle and/or bone pain
- kidney problems, such as changes in the colour or amount of urine passed
- unexpected bleeding or bruising
- bad diarrhoea and/or abdominal pain
- blistering and/or peeling of the skin, lumps on the body or patches of dry skin
- loss of appetite, nausea and vomiting.

If you have not had chickenpox and come into contact with someone who has chickenpox or shingles, or you develop chickenpox or shingles, you should stop taking the mycophenolate and see your GP immediately. You may need antiviral treatment, because chickenpox and shingles can be severe in people taking mycophenolate, as it affects the immune system.

Rarely, people are allergic to mycophenolate. If you have an allergic reaction, the medication will have to be stopped. Symptoms of an allergic reaction include a skin rash, wheezing, shortness of breath and swelling of the face, lips, tongue or throat.

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

As mycophenolate can sometimes cause liver or kidney problems, your doctor will arrange for you to have a blood test before you start treatment. This is so we have a 'baseline' set of liver and kidney results and can see if any changes occur once treatment starts.

It is important to have your blood tested regularly, to check for early signs of changes. These blood tests show if the mycophenolate is working and whether you are developing any side effects.

The blood tests should be carried out at your GP surgery and will need to include:

- full blood count
- urea and electrolytes
- liver function tests.

You will need to have a blood test every week for the first 6 weeks, then once a month for the first year of treatment, then every two months after this time.

## **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 that are not prescribed by a doctor (such as over the counter medications or herbal remedies).

It is safe to drink alcohol in moderation whilst on mycophenolate, but this may make any diarrhoea and nausea worse. It may also cause liver problems or making existing liver problems worse.

## Vaccinations

Seasonal vaccination against influenza is recommended for people of any age while they are taking mycophenolate, and also vaccination with pneumococcal polysaccharide vaccine against pneumonia.

Mycophenolate Mofetil does not appear to increase the risk of catching influenza, but the illness can be much more severe if you catch it whilst taking this medication.

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

## Contraception and pregnancy

The use of mycophenolate in pregnancy has been associated with birth defects and pregnancy loss, so it should not be used in pregnancy.

Before starting mycophenolate, if you are female and still able to become pregnant, you will need to have two negative result pregnancy tests, carried out 8 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 at the same time (for example, the contraceptive pill and barrier methods, such as condoms) during treatment with mycophenolate and for 6 weeks after stopping treatment.

If you become pregnant whilst taking mycophenolate, do not stop taking the medication. Contact your GP immediately.

If you are male, you should use condoms during treatment (even if you have had a vasectomy) and for at least 90 days after stopping treatment, as mycophenolate can affect your sperm. If you have a female partner, they should also use effective contraception whilst you are on this treatment and for 90 days after your last dose.

## **Mycophenolate Mofetil and breastfeeding**

If you are breastfeeding you should not take mycophenolate. The medication could pass into the breast milk and the risk to the baby is unknown.

## **What happens if I need an operation?**

Before your operation or procedure, let the doctor or nurse know you are taking mycophenolate. You may need to have a course of antibiotics before or after the procedure, as your immune system is less able to prevent or fight off infection.



## **Where can I find more information?**

For more information, speak your GP or a member of the ILD team.

### **Oxford ILD Team**

Telephone: **01865 227 050**  
(9.00am to 5.00pm, Monday to Friday)

Email: **[oxford.ild@ouh.nhs.uk](mailto:oxford.ild@ouh.nhs.uk)**

# Notes

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## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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