

Patient information factsheet

Mycophenolate for interstitial lung disease (ILD)

This factsheet contains useful information about the medicine mycophenolate mofetil (MMF). It explains what interstitial lung diseases (ILDs) are, how mycophenolate is used to treat some ILDs and the common side effects of taking the medicine. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to your doctor, nurse or pharmacist.

What is interstitial lung disease (ILD)?

ILD is an umbrella term for a number of different types of diseases that can affect your lungs. ILDs can cause scarring in your lungs, inflammation in your lungs or a combination of both. If your ILD mainly causes inflammation, we may prescribe you immunosuppressant drugs (drugs that reduce the strength of the body's immune system), such as mycophenolate. Other medications that can be used to treat ILDs include corticosteroids (prednisolone), azathioprine and methotrexate.

What is mycophenolate?

Mycophenolate is an immunosuppressant drug that is used to control your body's immune system in conditions where it is overactive and causing harm. It is used to treat a wide range of ILDs, including:

- hypersensitivity pneumonitis (HP)
- connective tissue disease associated interstitial lung diseases (CTD-ILD), such as rheumatoid arthritis, lupus, Sjögren's syndrome and anti-synthetase syndrome

If left untreated, inflammation in the lungs may develop into permanent scarring or pulmonary fibrosis. Mycophenolate helps to control the inflammation and protects your lungs from ongoing damage, but it may not improve your symptoms (breathlessness and a cough).

Please note that it may take up to three months for you to experience any benefit from taking mycophenolate. Your symptoms and lung function tests will be monitored, and you may need a CT scan (a type of scan that uses x-rays to produce detailed images of the inside of the body) to assess your response to the medication.

How to take mycophenolate

- Mycophenolate is usually taken twice a day (morning and evening).
- The tablets should be swallowed whole with a glass of water. Do not crush or chew them.
- Mycophenolate may be taken with or without food.
- It is important that you handle the tablets as little as possible.

Patient information factsheet

Dose to take

Your doctor will prescribe the most appropriate dose for you. You will usually be started on a low dose to reduce the risk of developing any side effects. If you tolerate the medication well, the dose may be increased by your doctor.

It may take 6 to 12 weeks before you feel any benefit from taking mycophenolate. Do not stop taking the medication unless you experience severe side effects. Even when your symptoms start to improve, make sure you continue taking the medication, as it will help to keep the disease under control.

What to do if you forget to take your medication

- Never take two doses at once.
- If you forget to take your mycophenolate, take it as soon as you remember. However, if it is close to the time your next dose is due, miss the first dose and only take the next dose at the usual time.
- Contact your doctor or pharmacist if you are unsure of what to do.
- If you take more tablets than you have been told to take, please contact your doctor immediately.

Side effects

Mycophenolate has been used for many years and most people do not develop any problems. However, it can occasionally cause some side effects.

The most common side effects are:

- nausea (feeling sick)
- diarrhoea (loose stools)
- vomiting (being sick)
- stomach pain

Other possible minor side effects are:

- loss of appetite
- feeling tired, or having trouble falling or staying asleep
- dizziness or drowsiness
- muscle spasms, tremors or chills
- anxiety or changes in mood
- headache
- pain (especially in the back, muscles or joints, or on passing wee)

If you experience any of the minor side effects listed above, please speak to your doctor or ILD clinical nurse specialist as soon as possible.

Potentially serious side effects are:

- stomach or mouth ulcers
- fever or infections
- kidney problems (these may cause a change in the colour of your wee or the amount of wee you pass)
- unexpected bleeding or bruising
- jaundice (yellowing of the skin and the whites of eyes)
- rash, blistering of skin or peeling of skin

Patient information factsheet

If you experience any of the potentially serious side effects listed on the previous page, please stop taking mycophenolate and seek urgent medical attention from your GP or your nearest emergency department. Please also contact our ILD clinical nurse specialist to inform them of your reaction to mycophenolate.

Skin protection

Although it is rare, there is a slightly increased risk of cancer in people taking mycophenolate. Due to this risk, you should always make sure you protect your skin. This includes:

- not sunbathing
- wearing suitable clothing (such as long sleeves and a sun hat)
- using sunscreens with a sun protection factor (SPF) of at least 30 and a star rating of at least four

If you notice any new swellings or lumps on your body, or changes in your skin that last more than two weeks, you should inform your GP immediately. For further advice on skin care and the sun, please visit www.skinhealthinfo.org.uk

For the full list of potential side effects that may occur with mycophenolate, please read the leaflet supplied with your medicine.

Infections

Mycophenolate can increase your risk of infection. Stop taking mycophenolate and tell your doctor or ILD clinical nurse specialist immediately if you develop any of the following:

- a sore throat
- a fever
- any other symptom of infection
- unexplained bleeding or bruising
- any other new symptom that concerns you

Chickenpox

You should see a doctor immediately if you come into contact with someone who has chickenpox or shingles, especially if you have never had chickenpox or not had a chickenpox vaccination. These infections can be more severe if you are taking mycophenolate and you may require antiviral treatment.

Vaccinations

As mycophenolate suppresses (weakens) your immune system, you should not have any live vaccinations, such as the shingles or yellow fever vaccine. Having live vaccines while you are on mycophenolate may cause an infection and the vaccine may not work properly.

Please discuss vaccinations with your doctor, as some are safe and recommended, such as the Pneumovax and flu vaccinations.

Blood tests

Regular blood tests are important while taking mycophenolate, to check for any unwanted effects on your liver function or blood cell production. We will give you blood test forms at your ILD outpatient appointment. These forms will allow you to have blood tests at either your GP surgery or local hospital.

Blood tests are required:

- Weekly for the first two months

Patient information factsheet

- Then every two weeks until your target dose of mycophenolate has been achieved
- Then monthly for the first year
- Then every two months after the first year

Taking other medicines with mycophenolate

Mycophenolate may react with a number of medications. If you take any other medication (including over-the-counter medication and herbal remedies), please let your doctor or pharmacist know before starting mycophenolate so that they can check whether it is safe to take. You should also discuss any new medications with your doctor or pharmacist before starting them.

Prednisolone

Taking prednisolone with mycophenolate is safe. If you are already taking prednisolone before starting mycophenolate, your prednisolone dose may need to be reduced. Please discuss this with your doctor.

Alcohol

You should only drink alcohol in moderation while taking mycophenolate, as they can both affect your liver. It is important that you do not exceed the government's recommended safe limits which advise that you should not drink more than 14 units of alcohol per week.

Pregnancy and breastfeeding

Advice for women

Mycophenolate can cause harm to unborn babies, so you should not take mycophenolate if you are pregnant or are planning on becoming pregnant. If there is any chance that you could be pregnant, you will need to have a pregnancy test before starting treatment.

If you are taking mycophenolate and thinking of starting a family, please discuss this with your doctor. Please note that you must stop taking mycophenolate for at least six weeks before you try to become pregnant, as the harmful effects remain for this length of time.

It is important that you use a reliable form of contraception before starting treatment, during treatment and for at least six weeks after stopping treatment.

Advice for men

It is important that while you are taking mycophenolate, both you and your female partner use reliable contraception during treatment and for at least 90 days after stopping treatment.

If you are taking mycophenolate and thinking of starting a family, please discuss this with your doctor.

If your female partner has become pregnant while you are taking mycophenolate, or within 90 days of stopping treatment, please discuss this with your doctor.

Breastfeeding

You should not breastfeed while you are taking mycophenolate, as the drug can pass into the breast milk and may be harmful to your baby.

For further information about mycophenolate and pregnancy, please visit www.medicines.org.uk/emc/files/pil.1103.pdf

Patient information factsheet

Contact us

If you have any questions or concerns about your condition, please contact your GP or our ILD clinical nurse specialist.

ILD clinical nurse specialist

Telephone: **023 8120 6277** (during working hours or leave a message)

For further information about the medication, please read the leaflet which comes inside the box with your mycophenolate. You can also contact our medicines helpline.

Medicines helpline

Telephone: **023 8120 6907** (Monday to Friday, 9am to 6.30pm)

Email: **medicinesadvice@uhs.nhs.uk**

Useful links

If you would like more information on living with ILD, please visit the websites below:

www.wildsupport.co.uk

www.blf.org.uk

www.actionpulmonaryfibrosis.org

www.arthritisresearchuk.org

For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**