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Royal Brompton & Harefield **NHS**
NHS Foundation Trust

Royal Brompton Hospital

Mycophenolate monitoring

and dosage record for
respiratory patients with
interstitial lung disease





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This leaflet gives you general information on mycophenolate monitoring. It does not replace the need for personal advice from a healthcare professional. Please ask us if you have any questions.

This booklet holds information about your immunosuppression treatment. Please keep this booklet with you all the time and show it to any person treating you including your doctor, pharmacist and nurse.

Your details

Name:

Address:

Date of birth:

Contact telephone number:

Important information

- This medicine has been prescribed for **you alone**. Do not give it to anyone else, even if their symptoms are the same as yours.
- **Take this medication only as prescribed by your doctor. Do not change anything without checking with your doctor first.**



Contact details for the healthcare team looking after you:

Indication for treatment:

Consultant name and contact no:

GP surgery address and telephone:

Community pharmacy address and telephone:

For further information on medicines, please contact the pharmacy medicines information patient helpline on **020 7351 8901**, 10am-5pm, Monday to Friday.

For advice outside working hours, call the NHS 111 service free of charge from any phone by dialling **111** or phone Royal Brompton Hospital switchboard on **020 7352 8121** and ask for the operator. You can ask the operator to connect you to the on-call respiratory doctors.

Mycophenolate mofetil (mye koe fen' oh late)

Mycophenolate is an immunosuppressant drug. Immunosuppressant drugs are used to dampen down the body's immune system in conditions where the immune system is overactive, and reacts against your own body.

This drug can be used:

- To prevent organ rejection in patients who have had an organ transplant.
- In lung disease to reduce inflammation, which can contribute to your symptoms. (If you take prednisolone, taking an immunosuppressant will usually mean that your dose of prednisolone can be reduced.)
- In other conditions, e.g. rheumatoid arthritis.

Mycophenolate is normally taken twice a day. Your doctor will decide the dose you need.

If you take any other medicines, please let your doctor know so that he / she can check that they are safe for you to take with mycophenolate.

You should inform your doctor if you have or have ever had any problems with your digestive system, e.g. stomach ulcers.

You will start on a low dose of mycophenolate for one month to check that you do not experience any side effects or problems from this treatment. Your dose will gradually be increased to the maximum dose as prescribed by your doctor. Mycophenolate does not work immediately and it may be six to 12 weeks before you notice any benefit.

Your recommended dose (twice daily):

Test dose	mg twice daily	Start date:
Increased dose	mg twice daily	Start date:
Increased dose	mg twice daily	Start date:
Increased dose	mg twice daily	Start date:

Side effects

This is not the full list of possible side effects; please refer to the patient information leaflet supplied with your medicine for a complete list.

Some of the side effects of mycophenolate are listed below. Tell your doctor straightaway if you notice any of the following side effects while taking mycophenolate:

- nausea and vomiting
- constipation or diarrhoea
- stomach pain
- loss of appetite
- unexpected bleeding or bruising
- stomach and mouth ulcers
- feeling tired, difficulty falling asleep or staying asleep
- dizziness, drowsiness, muscle spasms, anxiety, changes in mood, headache, tremor, chills
- pain, especially in the back, muscles, or joints or on passing urine
- infection such as infections of the skin, mouth, stomach and intestines, lungs and urinary tract.

Patients taking mycophenolate may be more likely to develop different kinds of cancers, including skin cancers. Limit your time in the sun, cover up with clothing, and use high factor sunscreen.

While you are taking mycophenolate, your doctor will arrange for you to have regular blood tests. This will help to check for any unwanted effects on your liver or blood cell production.

Your GP should arrange for you to have a blood test every week for the first month of therapy and then every two weeks until your target dose has been reached. Your blood should then be tested monthly for the first year and every second month after that.

It is important that you do not take mycophenolate unless you are having regular blood tests.

Pregnancy and breastfeeding

- Mycophenolate can cause problems for unborn babies.
- Make sure that you are not pregnant before starting to take mycophenolate.

- Treatment will only start after a negative pregnancy test.
- Use adequate contraception before starting treatment, during treatment and for six weeks after stopping treatment. You should use two reliable forms of contraception simultaneously.
- Please contact your doctor immediately if you become pregnant while on treatment.
- Do not breastfeed while you are taking mycophenolate as a small amount of the drug can pass into breast milk.

Contraceptive advice for men

- Use condoms during treatment and for at least 90 days after stopping treatment. This includes vasectomised men.
- Female partners should use highly effective contraception whilst you are on treatment and for 90 days after the last dose of mycophenolate.
- Do not donate semen during treatment or for 90 days after stopping treatment.



What else do I need to know about mycophenolate treatment?

Because these tablets / capsules work by suppressing the immune system, you may have a decreased ability to fight infection.

If you get any signs of infection (sore throat or fever), experience jaundice (yellowing of the skin or whites of the eyes), or any unexplained bleeding or

bruising, tell your doctor immediately.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should see your doctor immediately as you may need special treatment.

Can I take other medicines with mycophenolate?

Always ask your doctor or pharmacist about any other medicines before you start to take them. This includes over-the-counter medicines, herbal and alternative remedies. All of these can interact with mycophenolate and affect your treatment.

The symptoms you are trying to treat with these other medicines may be a sign that mycophenolate is not working safely for you. It is important for your doctor or pharmacist to know so they can help you.

Keep a record of any symptoms and discuss them with your doctor.

While you are taking mycophenolate, and for a short while after you stop, do not have any live vaccines, such as yellow fever. Because your body's resistance is lower, this may cause you to get an infection from the vaccine and the response to the vaccine may be reduced. Pneumovax and yearly flu vaccines are safe and recommended. Discuss any other vaccinations with your doctor first.

What do I do if I forget to take my medicine?

If you forget to take your medicine you can take it as soon as you remember, but **never** take two doses at once.

If you are unsure what to do, please contact your doctor for advice.

Other advice and precautions

- Swallow your tablets whole with a glass of water. Do not break or crush them.
- Handle the tablets as little as possible.
- Store them at room temperature and out of reach of children.
- There is no particular reason for you to avoid alcohol while taking mycophenolate, but drink it in moderation.
- Do not donate blood during treatment or for at least six weeks after stopping treatment.

Things you must tell medical staff

- If you need emergency treatment, please tell the medical staff helping you that you are taking mycophenolate.
- If you are pregnant, breastfeeding or allergic to any medicine, please tell your doctor before he/she prescribes any new medicines.
- If you take more tablets than you have been told to take, please contact your doctor immediately.

Over-the-counter medicines

The information in this booklet will help a pharmacist determine if over-the-counter medicines are suitable for you.

Monitoring results

Please ask the person responsible for prescribing / monitoring your treatment to record your test results below:

Date of blood test				
Dose				
Hb Male 13.4-16.6g/dL Female 11.5-15.1g/dL				
MCV 84-98fL				
WBC 5.1-11.4 $10^9/L$				
Platelets 147-397 $10^9/L$				
Neutrophils 2.0-7.5 $10^9/L$				
Lymphocytes 1.3-3.7 $10^9/L$				
ALT 0-40 IU/L				
Alk phos 38-126 U/L				
CRP 0-10 mg/L				
Urea 2.5-6.5 mmol/L				
Creatinine 60-120 $\mu\text{mol/L}$				
Total bilirubin 3-24 $\mu\text{mol/L}$				
Next test date				

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What the terms mean

Hb: The oxygen-carrying component of red blood cells.

MCV: The average volume of a red blood cell.

WBC: White blood cells.

Platelets: An irregular, disc-shaped element in the blood that helps in blood clotting.

Lymphocytes: Small white blood cells that play a large role in defending the body against disease. They are responsible for immune responses.

Neutrophils: White blood cells filled with enzymes used to kill and digest micro-organisms.

ALT: An enzyme normally present in the liver and heart cells that is released into the blood stream when the liver or heart is damaged. Abnormally high ALT levels may indicate that the liver is not functioning normally.

ALK phos: An enzyme made in the liver that is usually released into the blood during injury. Abnormally high levels may indicate some liver damage.

CRP: A component of blood that rises in response to inflammation in the body. This rate increases with more inflammation.

Urea and creatinine: Substances normally cleared from the blood by the kidneys. Increased blood levels of urea and creatinine indicate that the kidneys may not be functioning normally.

Your notes



Your notes

If you have concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call PALS on:

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

You can also email pals@rbht.nhs.uk. This is a confidential service.

Royal Brompton Hospital
Sydney Street
London
SW3 6NP
tel: 020 7352 8121
textphone: (18001) 020 7352 8121

Harefield Hospital
Hill End Road
Harefield
Middlesex
UB9 6JH
tel: 01895 823 737
textphone: (18001) 01895 823 737

Website: www.rbht.nhs.uk

إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosurteki bilginin Türkçe tercumesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercumenin gerçekleşmesini en kısa zamanda ayaracaktır.

