Mycophenolate mofetil

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This is an information leaflet for people who are considering starting mycophenolate. It answers lots of the frequently asked questions and can guide you with your decision making as to whether this is the right drug for you. However, this booklet is not intended to take the place of the manufacturer’s guidance on the medication and should always be read in conjunction with the manufacturer’s recommendations.

If you have any more questions once you have read this leaflet, please contact your doctor or nurse specialist.

**What is mycophenolate?**

Mycophenolate mofetil is a tablet which may be recommended by your consultant to help treat your autoimmune condition. This drug and those with similar properties are often referred to as immunomodulators. Autoimmune disorders are when your body’s immune system becomes overactive and begin to attack healthy cells in your body. Mycophenolate reduces the activity of the immune system, modifying the underlying disease process to limit or prevent tissue damage and disability. Some of the conditions it may be used for include:

- **Neuroimmunological indications including:**
  - Autoimmune encephalitis
  - Stiff person syndrome
  - Neurosarcoidosis
  - Neuromyelitis optica
  - Myasthenia gravis

- **Inflammatory muscle disease or myositis such as:**
  - Dermatomyositis
  - Polymyositis
  - Overlap myositis

- **Vascular indications including:**
  - Vasculitis
• Other rheumatological and medical conditions such as:
  - Rheumatoid arthritis
  - Lupus (SLE)
  - Asthma
  - Crohn’s disease
  - Eczema
  - General allergies

• Prevention of organ rejection after transplantation.

How do I take it?
Mycophenolate comes in tablet, capsule or oral solution and is taken once or twice daily with water, preferably with food. It must be swallowed whole and not chewed or crushed.

What are the possible side effects?
As with all medications, mycophenolate can cause side effects. The most common side effects include nausea, vomiting and diarrhoea. Dividing up the total daily dose throughout the day can reduce these symptoms. Any side effects you have should improve after a few weeks once your body has adjusted.

Unless you have severe side effects it is important to keep taking mycophenolate. Even if it does not seem to be working at first, you should continue with the medication at the prescribed dose until instructed otherwise. Although symptoms may improve, this drug will keep the disease under control.

Occasionally mycophenolate may also cause abdominal pain and very rarely inflammation of the lungs, leading to breathlessness. If this happens to you, consult your doctor.

Although very uncommon, there is an increased risk of certain types of cancer in people who use mycophenolate. As the development of skin cancer is an increased risk, you will need to limit your exposure to sunlight and UV light by wearing clothing
that covers exposed skin, using a high factor sunscreen and wearing sunglasses where appropriate. Discuss this with your doctor or clinical nurse specialist if you are concerned.

Other reported side effects include allergic reactions, high temperature, tiredness, headache, difficulty sleeping, hair loss, a rash and changes in blood pressure.

Mycophenolate can affect the blood, liver and kidneys, causing some patients to be more likely to develop infections and more likely to bruise easily. You will require blood tests monitoring whilst taking mycophenolate. You will be told whether the blood tests will be carried out at the hospital or your local GP surgery.

You must not take mycophenolate unless you are having regular blood checks.

Is infection a side effect of mycophenolate treatment?

As mycophenolate affects the immune system, it can make you more likely to develop infections. You should tell your doctor or clinical nurse specialist straight away if develop any of the following:

- A sore throat
- High temperature above 37.5°C or any other signs of infection
- Unexplained bruising or bleeding
- Yellowing of the skin or eyes (jaundice)

If any of these symptoms are severe or you become very unwell, you should stop the mycophenolate and seek immediate medical attention, explaining you have been taking mycophenolate. You should also see your doctor if you develop chickenpox or shingles or come into contact with someone who has these conditions. These infections can be severe in people on mycophenolate. You may need antiviral treatment, and you may be advised to stop taking mycophenolate until you’re better.
Is there an alternative?

There are alternatives if mycophenolate is not well tolerated. Drugs such as azathioprine and methotrexate have a similar effect on the immune system. If the disease is not adequately controlled by mycophenolate, then stronger medications, such as cyclophosphamide, might also be considered.

These drugs can be used instead of steroids. As your medical team may have discussed with you, steroids if used long-term can have significant side effects. Mycophenolate usually takes longer than steroids to work. It can take up to 12 weeks, so they may not have an immediate effect on symptoms. Usually doctors will start you on mycophenolate while you are taking steroids.

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. Contact your doctor immediately if you have taken too much mycophenolate. If you begin to miss doses frequently, please let your doctor know.

Will mycophenolate interfere with my other medicines?

Before you start any new medicines, you must check with your doctor or pharmacist if they will interact with mycophenolate, especially those that are not prescribed by a doctor (such as over the counter medication or herbal remedies). Do not take over the counter preparations or herbal remedies without discussing this first with your healthcare team.

You can drink alcohol whilst on mycophenolate. However, it is recommended you only drink small amounts.
Can I still have vaccinations?

When taking mycophenolate, it is usually recommended that you avoid live vaccines, such as those for yellow fever or shingles. Sometimes a live vaccine may be necessary, for example the rubella vaccination in women of childbearing age. However speak to your medical team about this as there may be some exceptions. Pneumococcal vaccine and the yearly flu vaccines are recommended. Mycophenolate 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.

Can I still take mycophenolate if I am pregnant or breastfeeding?

Mycophenolate **should not** be used in pregnancy as it has been associated with birth defects and miscarriages.

Before starting mycophenolate, if you are female and of child bearing age, you will need to have two negative result pregnancy tests, carried out 8-10 days apart. You should use two methods of contraception, for example, the contraceptive pill and a barrier method, such as condoms. This should continue up to 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 it can affect your sperm. If you have a female partner, they should also use effective contraception whilst you are being treated and for 90 days after your last dose.

You should not breastfeed if you are on mycophenolate. The drug may pass into the breast milk and could be harmful to your baby.
Please use the space below to write down any questions you may have and bring this with you to your next appointment.
The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.