

# Mycophenolate Mofetil (MMF)

Information for Parents & Carers



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## Introduction

This leaflet contains information about the use of Mycophenolate Mofetil (MMF) in children in the management of rheumatological conditions.

### It tells you:

- how the medicine works
- how it should be given
- whether there are any side effects.

Please also read the leaflet called Medicines for Children - Information for parents and carers and any information provided by the manufacturer in the medicine package.

## Why have I been given this leaflet?

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with this treatment.

For most medicines, information is provided by the manufacturer in the medicine package. Mycophenolate mofetil does not have a licence for use for lupus, uveitis or scleroderma in children so the leaflet in the medicine package doesn't tell you everything you need to know. We have written this leaflet to give you some extra information.

## What is mycophenolate mofetil and how does it work?

Mycophenolate mofetil has been shown to be an effective treatment for a number of inflammatory conditions in

children including systemic lupus erythematosus, uveitis, juvenile dermatomyositis and scleroderma. It reduces the activity of the body's immune system, slows down the disease activity and brings the disease into remission.

Mycophenolate mofetil does not work immediately and it may be up to twelve weeks before an effective response is noticeable.

### **When should mycophenolate mofetil not be taken?**

You/your child should not take this medicine if they have an unexplained illness or prolonged fever.

You/your child should not take this medicine if allergic to any of the ingredients listed.

Mycophenolate mofetil is not known to affect fertility, but any young female person should avoid pregnancy whilst taking mycophenolate mofetil and for at least 6 weeks after stopping the drug, as mycophenolate mofetil could damage the unborn baby. Any young male person needs to use barrier contraception for 90 days after stopping the drug, as this could also damage the unborn baby.

This medicine should be used with extra care if your child has kidney problems or gastro-intestinal disease.

Please tell your doctor if your child has any of the conditions above or those listed in the manufacturer's leaflet.

### **How should I give mycophenolate mofetil?**

Mycophenolate mofetil is taken by mouth and comes as a capsule, tablet or liquid. It is usually taken twice a day and

is best taken on an empty stomach. The tablets and capsules should be swallowed whole and not crushed or chewed.

The dose you/your child starts on is usually increased after approximately one month. You/your child may need to take this medication for years. Keep giving the medicine until your doctor tells you to stop.

If you miss a dose of mycophenolate mofetil, give it as soon as you remember. If it is almost time for the next dose, take only that dose. Do not take double dose.

If you/your child is sick within 15 minutes of giving a dose repeat the dose, otherwise wait until the next dose is due.

## Are there any side effects?

All medicines can cause side effects. The manufacturer's leaflet contains a comprehensive list of the known side effects for this medicine. Everyone reacts differently to medicines. Your child may have some side effects or none at all.

Mycophenolate Mofetil can sometimes cause a diarrhoea, nausea, tummy upset or rash. Please contact your doctor or rheumatology nurse if they carry on for more than a few days or make your child feel unwell.

**More rarely mycophenolate mofetil can cause a reduction in the production of certain blood cells. It can also increase the risk of infections. If you/ your child has any of the following effects; unexplained bruising or bleeding, repeated infections or unexplained temperatures, you should stop giving the mycophenolate mofetil and contact your doctor as soon as possible.**

Mycophenolate mofetil may also affect how the kidneys and liver work. This is monitored by regular blood tests.

As with all immunosuppressant medication we would recommend safe sun exposure, and in particular avoiding sun burn. It is therefore recommended that sun protective clothing is used and high factor sunscreen applied regularly in sunny weather due to an increased risk of long term skin damage.

### **Are there any special checks required, whilst on mycophenolate mofetil?**

Checks are required to detect any problems that might occur with the bone marrow, kidney or liver.

Blood tests will be needed monthly until the dose is stable and then to once every three months. Blood test need to go back to monthly with any dose increases.

### **Will mycophenolate mofetil affect any other medicines?**

Tell your doctor or pharmacist about all the other medicines you/your child take(s). This includes any medicines prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

If you are/your child is prescribed a new medicine, or you want to buy a medicine (for your child), it is important that you tell the doctor or pharmacist about all the medicines that you/your child takes, including mycophenolate mofetil. You should also tell your/your child's dentist next time you see him/her.

Please arrange an influenza vaccine every winter, due to the immunosuppressive nature of the medicines. You may also need a pneumococcal vaccine.

## **So this medicine does not have a licence. What does this mean?**

It tells you why unlicensed medicines are sometimes used.

## **Why does mycophenolate mofetil not have a licence for use in children?**

Sometimes a medicine has been licensed for a certain use in adults and later use shows that it works for a similar illness in children. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money and sometimes the manufacturer decides it is not worth their while.

Mycophenolate mofetil is made by the manufacturer for use in children to prevent rejection following organ transplants, but it has also been shown to help inflammatory conditions.

Remember that your doctor will have thought carefully about which medicine is best for your/your child's condition.

## **Where should I store mycophenolate mofetil at home?**

Store mycophenolate mofetil in a cool, dry place, away from direct sunlight. Check the expiry date, particularly of liquid preparations.

It is important that all medicines are stored out of reach of children.

## Where do I get a further supply?

Once the medicine has been started and the blood tests are stable, the consultant will write to your GP and ask if they can take over the prescribing of this medicine. Once your GP is prescribing your mycophenolate mofetil, then this can be obtained from your local chemist. Please allow your local pharmacy a week to obtain the mycophenolate mofetil, as they will probably not keep it routinely.

If the hospital consultant is responsible for the prescribing, you will be given enough to last until your child's next appointment. However, if you need further supplies, please contact the specialist nurses, who can arrange a prescription.

## How can I find out more?

This leaflet has been written to provide general information about Mycophenolate Mofetil in children. If you have any further questions or concerns, please speak to your doctor or pharmacist.

<b>Children's Rheumatology Nursing Team</b>	<b>0113 392 0683</b>
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<b>Paediatric Rheumatology Secretary</b>	<b>0113 392 0666</b>
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