Neurology and Pharmacy directorate

Mycophenolate mofetil (MMF) for Myasthenia

Introduction
This leaflet provides information on a medicine called mycophenolate mofetil (MMF) when it is used to treat myasthenia gravis. After reading this leaflet you should have an idea about what to expect if you start taking MMF, for example, how well it works, and what side-effects you may experience.

What is myasthenia gravis?
Myasthenia gravis is an ‘autoimmune disease’. This means that your immune system (the body’s own defence system), which usually protects your body by fighting off infections such as the cold virus or measles, starts to attack a small part of your body. In people who have myasthenia gravis the immune system produces antibodies (a type of protein that circulates in the blood) which sticks to the muscle surface at the site where the nerves connect to the muscle fibres (the neuromuscular junction). These antibodies interfere with the transmission of chemical messages from the nerve branches to the muscle fibres. This results in fewer muscle fibres contracting and less power is therefore generated by the muscles. The symptoms of myasthenia gravis depend on which muscles are affected. For example, weakness of the muscles which move the eyes results in double vision, whilst weakness of the throat muscles may result in problems with swallowing.

What is mycophenolate mofetil (MMF)?
MMF is a type of medicine called an ‘immunosuppressant’. It reduces the production of antibodies by ‘damping down’ the activity of the body’s immune system. This helps messages getting through from the nerves to the muscles and muscle strength improves. Other immunosuppressants that have been used to treat myasthenia gravis include; prednisolone (a steroid), cyclophosphamide, ciclosporin, azathioprine, and tacrolimus.

When is mycophenolate mofetil (MMF) prescribed?
In patients with mild myasthenia gravis, medicines called acetylcholinesterase inhibitors (e.g. pyridostigmine) are usually prescribed to increase muscle strength. They work by increasing the effect of the chemical messenger (acetylcholine) which transmits information from the nerves to the muscles. If the symptoms cannot be controlled using these drugs the next stage of treatment is some form of immunosuppressant to help increase muscle strength.
Steroids such as prednisolone are the immunosuppressant which is usually used first. Some patients have other conditions, such as diabetes, where steroids are best avoided. In others, the myasthenic symptoms cannot be fully controlled with steroids, without them causing side effects.

In these patients, azathioprine is normally prescribed, either alone, or in conjunction with steroids. Combining azathioprine with steroids often allows a smaller dose of steroids to be used, minimising side effects, such as osteoporosis. If you are unable to tolerate azathioprine for any reason your doctor may prescribe MMF. Like azathioprine, the aim of treatment with MMF treatment is to reduce the dose of steroids, therefore lowering the risk of side-effects. MMF is normally prescribed with steroids. It is very unusual to take MMF alone for the treatment of myasthenia gravis.

How quickly does mycophenolate mofetil (MMF) work?

MMF does not work immediately. It may take 2-3 months before it starts to take effect, and the effect then builds up slowly but progressively. In some patients it may take longer than this (up to one year). The biggest improvement in symptoms is seen in the first year of treatment.

How well does mycophenolate mofetil (MMF) work?

Although there are very few studies that have looked at how well MMF works, in clinical practice it has been used very successfully to treat myasthenia gravis. Unfortunately, it is not possible to say exactly how many people get better after taking MMF, or to what extent their symptoms will improve.

When do I take mycophenolate mofetil (MMF)?

MMF is normally taken twice a day.

What dose should I take?

Your doctor will advise you. Usually you will start on a low dose and this is increased once a week (provided there are no problems with your blood tests) to a dose that is right for you. The dose you are given will depend partially on how well the medicine is working and if you have any side-effects.

What is the length of treatment?

Treatment is usually long term. If the disease goes into remission it may be possible to stop MMF, but many patients need to take it indefinitely.

What are the possible side-effects?

MMF is usually well tolerated; however, as with all medicines it can sometimes cause side effects. These usually go away as your body adjust to the new medicine. Some of the more
common side-effects include taste disturbances, diarrhoea, nausea, vomiting headache and dizziness. MMF can also cause a fast or fluttery heart beat.

Taking MMF can make you more likely to develop infections and to have problems with your liver. Tell your doctor immediately if you develop any of the following:

- A sore throat, a fever or any other signs of infection.
- Any unexplained bruising or bleeding.
- Jaundice (a yellow colouration of the skin and the white part of your eye) this indicates problems with your liver).
- Any other new symptoms after starting MMF.

If any of these symptoms are severe, you should stop the MMF and see your doctor immediately.

In addition to the above people who are taking this medicine for a long time have a small increased risk of developing skin cancer. In order to lower the risk of this happening you should avoid exposure to sunlight and apply a good quality sun cream (SPF 30 +) with UVA and UVB protection.

For more detailed information and a full list of side-effects, please read the leaflet that came with your medicine.

**Chickenpox and shingles**

As discussed above MMF reduces the activity of the immune system. This is particularly important if you have not had chicken pox before and you come into contact with some one who has chicken pox. This is because if people who take immunosuppressants get chicken pox or shingles can get very severe infections and they may need special treatment.

If you take MMF, try to avoid people who have chicken pox or shingles. If you come into contact with any one who has chicken pox or shingles contact your doctor as soon as possible.

**Do I need any special tests while on mycophenolate mofetil (MMF)?**

MMF can affect the bone marrow. This is monitored by checking your blood counts regularly. It can also sometimes cause liver problems. Therefore your doctor will arrange for you to have a blood test before you start treatment and then regular blood checks while on MMF. This is very important. You may be asked to keep a record booklet with your blood test results. Always bring this with you when you visit your GP or the hospital. You must not take MMF unless you are having regular checks.

**Can I take other medicines along with mycophenolate mofetil (MMF)?**

MMF may be prescribed along with other drugs in treating your condition. Some drugs interact with MMF (e.g. some antibiotics: metronidazole and norfloxacin), so you should discuss any new medications with your doctor before starting them. Always tell any other doctor treating you that you are taking MMF.
Do not take ‘over-the-counter’ preparations without discussing this first with your doctor or pharmacist.

Can I have immunisations while taking mycophenolate mofetil (MMF)?

Pneumovax® (a vaccine for pneumonia) and yearly flu vaccines are safe and recommended.

‘Live’ vaccines such as ‘rubella’ (German measles) or yellow fever are not recommended for people who are taking MMF. However, there are certain situations where the benefit of having a ‘live vaccine’ outweighs the risk, for example, vaccinating women of childbearing age against rubella. In this case, your doctor will discuss the risks and benefits of having a ‘live’ vaccine.

Can I drink alcohol with mycophenolate mofetil (MMF)?

There is no particular reason for you to avoid alcohol completely; however you should not exceed the recommended daily units.

What about pregnancy?

You must not become pregnant when taking MMF, and for six weeks after stopping treatment. This is because MMF is known to be harmful to the unborn baby. Effective contraception should be used before and during treatment as well as six weeks after stopping. If you become pregnant while taking MMF contact your doctor as soon as possible.

If you are planning on having a baby please seek the advice of your doctor well in advance so they can discuss how best to manage your myasthenia gravis during your pregnancy.

What about breastfeeding?

You should not breastfeed if taking MMF, the safety of this medicine in breastfeeding has not been established.

Useful websites/contacts

- Myasthenia Gravis Association
  - Address: The College Business Centre Uttoxeter New Road, Derby DE22 3WZ
  - Tel no: 01332 290219 or Free Phone 0800-919922
  - Web address: www.mga-charity.org
For further information

- **Medicines information patient helpline:**
  Tel: 0191 2823016. Available from 9:00 to 4:00 pm. Monday to Friday (excluding bank holidays). This helpline is available for patients of the Newcastle Upon Tyne Hospitals, to answer any questions they may have regarding their medicines.

- The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS. You can contact them on freephone 0800 032 02 02 or e-mail northoftynepals@nhct.nhs.uk.

- If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful.

Information produced by (Jenny Whitehall, Priti Sharma, Tim Walls, and Diane Palmer)
Date March 2013
Review date: March 2015