



Mycophenolate mofetil (MMF) to treat immune-mediated neurology conditions: information for families

Mycophenolate mofetil (MMF) is an immunosuppressant, that is, it damps down the immune system. This information sheet from Great Ormond Street Hospital (GOSH) explains about the use of mycophenolate mofetil (MMF) to treat immune-mediated neurology conditions, how the treatment is given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from the side effects mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.

In the treatment of immune-mediated neurological conditions, mycophenolate mofetil (MMF) needs to be given twice daily even when your child is well (in remission). In patients where MMF causes an upset stomach, the drug can be given three or four times daily in smaller amounts as this is better tolerated.

The aim of this medicine is to control inflammation and put the disease into remission. Your child will not notice any immediate effects of taking MMF on the inflammation as it can take some weeks to start working. Most children take MMF for about two to three years. When your child has been in remission for a year or two, the dose may gradually be reduced and then stopped.

How is it given?

MMF is taken by mouth in the form of capsules, tablets or an oral suspension.

Who should not take MMF?

People with the following conditions should discuss taking MMF with their doctor:

- Hypersensitivity to mycophenolate mofetil (MMF) or any of its ingredients
- Pregnant, could be pregnant, trying to become pregnant or breastfeeding
- Existing kidney problems

What are the side effects?

- **Nausea, vomiting, abdominal pain and diarrhoea** – these symptoms can be reduced by starting with a low dose of MMF and increasing the dose gradually over time or increasing the number of times the medication is given each day.
- **Reduced white blood cell count** – leading to increased risk of infection
- **Hair thinning or loss**
- **Effect on liver function** – blood samples will need to be tested weekly for the first month to ensure there are no complications, then fortnightly for the next two months, then monthly until six

months after starting the medication. Blood tests will then be carried out every three to six months once your child is stable.

Interactions with other medications

Some medicines can react with MMF altering how well it works. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines. The following medicines are known to interact with MMF:

- Some antibiotics
- Some antivirals
- Iron supplements

Important

- Keep medicines in a safe place where children cannot reach them.
- Keep the MMF tablets, capsules or oral suspension at room temperature, away from bright light or direct sunlight and away from heat.
- If your doctor decides that your child should stop taking MMF or the medicine passes its expiry date, please return it to your pharmacist. Do not flush it down the toilet or throw it away.
- If you forget to give your child a dose and it is within a few hours of when the dose was due, give it as soon as you remember. Otherwise, do not give this dose but wait

until the next dose is due. Do not give a double dose.

- Your child will need to have regular blood tests with your family doctor (GP) or local paediatrician. These blood tests check for the side effects mentioned previously. You will be given a card to record these results – please remember to bring it to your child’s clinic appointment.
- Your child should NOT have any live vaccinations such as MMR, oral polio, chicken pox or BCG while taking MMF. Inactivated or killed vaccines such as influenza/flu, meningitis C, pneumococcal, hepatitis, Hib, tetanus, diphtheria, whooping cough/pertussis and the killed version of the polio immunisation are permitted if the patient is stable under treatment.
- If your child is on MMF and has not had chicken-pox but comes into contact with someone who has chicken pox or shingles (either face to face or longer than 15 minutes in the same room), you should report to your doctor immediately as your child may be at risk of developing a more severe form of the infection and may need special treatment with immunoglobulin. If your child gets chicken pox or shingles you should also report to your doctor immediately for aciclovir to be given. If you are unsure whether your child has had chicken pox prior to starting MMF, their immunity should be checked with a simple blood test at that time and the result entered on the parent-held monitoring card.

Useful numbers

- GOSH Switchboard 020 7405 9200
- Pharmacy medicines information 020 7829 8608 (Monday to Friday from 9am to 5pm)
- Clinical Nurse Specialist for Neuroimmunology 020 7405 9200 5051 or 0460

Disclaimer

Please read this information sheet from GOSH alongside the patient information leaflet (PIL) provided by the manufacturer. If you do not have a copy of the manufacturer's patient information leaflet please talk to your pharmacist. A few products do not have a marketing authorisation (licence) as a medicine and therefore there is no PIL.

For children in particular, there may be conflicts of information between the manufacturer's patient information leaflet (PIL) and guidance provided by GOSH and other healthcare providers. For example, some manufacturers may recommend, in the patient information leaflet, that a medicine is not given to children aged under 12 years. In most cases, this is because the manufacturer will recruit adults to clinical trials in the first instance and therefore the initial marketing authorisation (licence) only covers adults and older children.

For new medicines, the manufacturer then has to recruit children and newborns into trials (unless the medicine is not going to be used in children and newborns) and subsequently amend the PIL with the approved information. Older medicines may have been used effectively for many years in children without problems but the manufacturer has not been required to collect data and amend the licence. This does not mean that it is unsafe for children and young people to be prescribed such a medicine 'off-licence/off-label'. However, if you are concerned about any conflicts of information, please discuss with your doctor, nurse or pharmacist.