Oxford University Hospitals NHS Foundation Trust

Mycophenolate mofetil



This leaflet answers some common questions patients ask about mycophenolate mofetil.

Further information can be found in the information leaflet supplied by the manufacturer or from your pharmacist, IBD nurse specialist or doctor.

Why have I been started on this medicine?

Mycophenolate mofetil (also known as CellCept®) is sometimes prescribed for patients with chronic active inflammatory bowel disease that require continuous or repeated courses of corticosteroids and who have failed to respond to, or are intolerant of, other immunomodulator drugs like azathioprine, mercaptopurine and methotrexate. In common with these drugs, mycophenolate is not licensed for use in patients with inflammatory bowel disease, but there is evidence to support its use in this group of patients. It is more routinely used for patients with organ transplants.

How does it work?

Mycophenolate suppresses inflammation and 'turns-off' the activity of the immune system. It is often referred to as a "steroid sparing agent" or "immunomodulator". Mycophenolate can take several weeks to take effect.

How do I take it?

Mycophenolate mofetil comes in tablet or capsule form and is available in two different strengths – 250mg and 500mg. It is also available as an oral solution for those patients with swallowing difficulties. The dose should be taken with, or soon after food. The tablets or capsules should be swallowed whole – do not break or crush them.

The dose of mycophenolate used is usually between 250mg twice daily and 1g twice daily.

How long will I be taking it?

If tolerated, you will probably continue treatment for as long as your disease remains under control. You should not stop taking your medicine unless your doctor tells you to.

What happens if I forget to take a dose?

If more than six hours has passed from the usual time you take your dose then forget that dose and take the next dose at the normal time. Do not double the dose. If you take too much mycophenolate tell your doctor immediately.

What are the possible side effects?

The main side effect of mycophenolate mofetil is gastro-intestinal disturbances such as diarrhoea, nausea or vomiting. Taking the total daily dose in divided doses throughout the day can reduce this. Diarrhoea caused by mycophenolate treatment may resolve after some weeks if you continue with treatment. As mycophenolate mofetil suppresses your immune system you can develop blood disorders leading to weakness or breathlessness, a susceptibility to infections, and a tendency to bruise easily. The risks are increased if you are also on other immunomodulators.

Occasionally, mycophenolate mofetil may inflame the liver or result in acute abdominal pain due to pancreatitis (inflammation of the pancreas gland) and can cause an increase in blood sugars. As with any drug that affects the immune system, there may be an increased risk of lymphoma or skin cancer. You are advised to limit your exposure to sunlight and UV light by wearing protective clothing and using a high factor sunscreen.

Other reported side effects include hypersensitivity, fever, lethargy, headache, difficulty in sleeping, abdominal pain, hair loss, rash and effects on your blood pressure. See below for information about mycophenolate and pregnancy.

Do I need any special checks while on mycophenolate mofetil?

Although the effects of mycophenolate mofetil on the blood and liver are fairly uncommon, it is important that you have regular blood tests to check for early signs of changes in the blood. We recommend this is done at first every week for the first month and then at 2-3 monthly intervals. You should also have your blood checked if you experience side effects such as a sore throat (see below). The blood tests can be done at the clinic or, with agreement of your GP, at your local surgery.

What do I do if I experience side effects?

If you experience any signs of illness or side effects such as unexplained bruising, bleeding, sore throat, fever, cough, shortness of breath or malaise, yellowness of the skin or whites of the eyes or severe itching (a sign of liver damage), contact your doctor or pharmacist immediately. If you are in close contact with anyone who has chicken pox or shingles, inform your doctor as soon as possible.

Does mycophenolate interfere with my other medicines?

There are no significant interactions with other medicines. Always check with your doctor or pharmacist first if you start any new medicines, especially those that are not prescribed by a doctor.

You should avoid having 'live' vaccines whilst taking methotrexate e.g., mumps, measles and rubella (MMR), yellow fever, BCG, some typhoid vaccines, and varicella vaccines. If you require travel vaccines or your doctor, nurse or pharmacist advise that you need a vaccine, always tell the healthcare professional that you are taking mycophenolate. Seasonal vaccination against influenza and pneumococcal vaccines are also recommended for adults taking mycophenolate.

It is safe to drink alcohol in moderation whilst on mycophenolate, but it may aggravate diarrhoea and nausea.

Is mycophenolate OK in pregnancy and breastfeeding?

Contraception for women taking mycophenolate mofetil

If you are a woman of childbearing age (12-55 years) you must always use two effective methods of contraception before starting treatment, whilst on treatment and for 6 weeks after stopping treatment. You should contact us as soon as possible if think you may be pregnant due to ineffective contraception.

If you are a woman of childbearing age you must provide two negative pregnancy test before starting treatment and must follow the contraception advice given to you by your doctor. We advise using birth control prior to treatment, as pregnancy tests may not reliably detect pregnancy during the first month. Your doctor may request more than one test to ensure you are not pregnant before starting treatment.

Contraception for men taking mycophenolate mofetil

You must always use condoms during treatment and for 90 days after you stop taking mycophenolate mofetil. If you are planning to have a child, your doctor will talk to you about the risks and the alternative treatments.

Female partners of male patients should use effective contraception during treatment and for 90 days after discontinuation.

Pregnancy and breastfeeding

If you think you may be pregnant or are planning to have a baby, you should contact us for advice before taking this medicine.

Mycophenolate causes a very high frequency of miscarriage (50%) and severe birth defects (23-27%) in the unborn baby. Birth defects which have been reported include anomalies of ears, of eyes, of face (cleft lip/palate), of development of fingers, of heart, oesophagus (tube that connects the throat with the stomach), kidneys and nervous system (for example spina bifida (where the bones of the spine are not properly developed). Your baby may be affected by one or more of these.

There is a detailed booklet on pregnancy and IBD available on the OUH website (see link at end of leaflet) or from the Gastroenterology Outpatients Department at the John Radcliffe and Horton General Hospitals.

Breastfeeding

You should not breastfeed if you are taking mycophenolate.

Keep all medicines out of the reach of children. Never give any medication prescribed for you to anyone else.

It may harm them even if their symptoms are the same as yours.

Useful contacts:

Gastroenterology pharmacist: Tel: 01865 221 523 or email: ibd.homecare@nhs.net

IBD Advice Line:

Tel: 01865 228 772 or email: ibd.advice@nhs.net

Online patient information leaflet library:

www.ouh.nhs.uk/patient-guide/leaflets/

Further information

Please speak to the department where you are being seen if you would like an interpreter. You will find their contact details on your appointment letter. Please also ask them if you would like this information leaflet in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronically
- in another language.

We have tried to make this information meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They will be happy to help.

Author: Version 1 Sarah Blackburn, Gastroenterology Pharmacist, January 2002 Version 2, Sarah Cripps Gastroenterology Pharmacist 2010 Version 3, Lloyd Thomas & Sarah Cripps, Gastroenterology Pharmacists February 2019, June 2020 Verified by Professor SPL Travis, Consultant Gastroenterologist Guidance received from Divisional Patient Information Coordinator Review June 2020 May 2021



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