

Drug information

# **Mycophenolate**

## **MYCOPHENOLATE**

is used to treat conditions of inflammatory arthritis, most commonly ones affecting the joints, connective tissue and blood vessels

**VERSUS  
ARTHRITIS**

## Introduction

Mycophenolate (my-co-fen-o-late) is a drug that can help prevent your condition causing further damage to your body. You can discuss the benefits and risks of taking mycophenolate with your healthcare professionals before you start treatment, so you're able to make an informed decision.

## What is mycophenolate and how is it used?

Mycophenolate is sometimes prescribed under the names mycophenolate mofetil or mycophenolate sodium.

Mycophenolate has a number of uses. When it's prescribed as a disease-modifying anti-rheumatic drug (DMARD), it should help control your condition and reduce damage to your joints and other organs such as your lungs, kidneys and blood vessels.

Like all DMARDs, mycophenolate slows down how active your condition is, rather than just treating how its symptoms affect you. It works by reducing the activity of your body's immune system.

When your immune system is working properly, it protects you by fighting off infection and illness. But in inflammatory conditions, your immune system may attack parts of your body by mistake, such as your lungs, kidneys and blood vessels.

Mycophenolate is used to treat several different conditions, including:

- lupus and other connective tissue disorders, including scleroderma (skle-ro-derm-a)
- rheumatoid arthritis (roo-ma-toy-d arth-ri-tus)
- psoriatic arthritis (saw-ree-at-ik arth-ri-tus)
- conditions in which there's inflammation of blood vessels, such as vasculitis (vask-you-lie-tus).

It's sometimes also used as part of the treatment of inflammatory conditions affecting the eye, such as uveitis (you-ve-eye-tis), or bowel, such as Crohn's disease (Cr-oh-nz diz-eez).

Mycophenolate is also used after organ transplantation, as it helps to stop the immune system rejecting the new organ.

Mycophenolate doesn't work immediately. It may be up to four months before you notice any benefit.

## **When and how do I take mycophenolate?**

Mycophenolate is usually given as a capsule or as a tablet, depending on the dose you need, though it is also manufactured as an injectable infusion and an oral solution.

Your doctor or pharmacist will advise you about the correct dose. Usually you'll be advised to take one dose a day for the first week. This will then go up to two doses a day.

You shouldn't crush or chew mycophenolate. You should always swallow them whole. It's recommended that you take the capsule or tablet with food and water, as this can stop you feeling sick and getting stomach pains.

It's important to keep taking mycophenolate even if it doesn't seem to be working at first. It's also important to keep taking it when your symptoms start to improve, as this will help control your condition.

## **What if I miss a dose?**

Take your missed dose as soon as you remember, unless it's almost time for your next one. If you have missed a tablet, don't take any more than your regular dose to make up for it.

## What if I take too much mycophenolate?

If you think you have taken too much mycophenolate call your rheumatology team or the NHS helpline on 111 for advice.



You can also contact the NHS helpline team through their website at [111.nhs.uk](http://111.nhs.uk)

## Possible risks and side effects

Mycophenolate can cause a number of side effects, including:

- feeling sick (nausea) or being sick
- diarrhoea (dy-a-ree-ah)
- stomach pains.

Whilst you're taking mycophenolate, tell your doctor, rheumatology nurse or pharmacist straight away if you start experiencing any new symptoms or anything that concerns you. Let them know immediately if you have:

- a sore throat
- a fever
- flu-like symptoms
- a constant cough or problems breathing
- the sensation that your heart is beating unusually
- sudden weight loss
- unexplained bruising or bleeding
- unexplained changes in mood
- headaches – particularly if you don't usually get them
- acne or a skin rash
- swollen gums or an unusual taste in your mouth.

If any of these symptoms are severe, your doctor may advise you

to stop taking mycophenolate. But it's always best to talk to your doctor or a member of your rheumatology team before making any changes to your treatment.

You should see your doctor as soon as possible if you come into contact with anyone with shingles or chickenpox, or if you get them yourself.

These infections can affect you badly if you're on mycophenolate. You may need antiviral treatment, and your mycophenolate may be stopped until you're better.

### Tips to reduce your risk of infection

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry around a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you're a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

## Other complications

Although it's uncommon, there's a slightly increased risk of certain types of cancer, such as skin cancer, in people using mycophenolate. However, the link between the two is unclear.

Skin cancers can often be treated successfully when diagnosed early. To be on the safe side, make sure to wear sunscreen and regularly check your skin for any new spots or changes to your freckles or moles.

Very rarely, patients treated with mycophenolate can develop a serious condition called progressive multifocal leukoencephalopathy (pro-gress-iv mul-tee-fo-cul loo-ko-en-kef-a-lop-afy), also known as PML, which can damage the brain and spinal cord.

You must see your doctor immediately if you notice any of the following symptoms:

- pins and needles
- weakness, shaky movements or unsteadiness
- sight loss
- speech problems
- changes in behaviour or mood
- difficulty moving your face, arms or legs.

Mycophenolate can affect the blood count and can sometimes cause liver or kidney problems. As a precaution, your doctor will arrange for you to have a blood test before you start treatment and regular blood tests while you're taking mycophenolate. Keep a note of when your blood tests are due and remind your doctor about them.

## **Taking other medicines**

Mycophenolate may be prescribed along with other drugs to treat your condition. But some drugs can interact with mycophenolate.

Before you start any new medication it's always a good idea to talk to your doctor first to make sure the treatments are okay to take together.

You can carry on taking non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen or painkillers, if needed, unless your doctor advises otherwise.

However, you shouldn't take over-the-counter preparations or herbal remedies without first discussing them with your doctor, rheumatology nurse specialist or pharmacist.

You should tell any other healthcare professionals treating you such as doctors, pharmacists, dentists or nurses, that you're taking mycophenolate.

## **Vaccinations**

If you're taking mycophenolate, you should avoid live vaccines, such as yellow fever. However, in certain situations a live vaccine may be necessary, so speak to your pharmacist or doctor about this for their advice.

It's a good idea to get the pneumococcal vaccine (new-mow-cok-al vak-seen), to protect you against the most common cause of pneumonia, and your yearly flu vaccines. These are both safe to have while you're being treated with mycophenolate.

## Surgery

If you're going to have an operation, discuss this with your rheumatology team. They will tell you whether you should continue taking your mycophenolate before your operation.

## Alcohol

Mycophenolate and alcohol can both affect your liver, so you should only drink alcohol in small amounts.

Government guidelines say both men and women should have no more than 14 units of alcohol a week, and that you should spread these through the week rather than having them all in one go.



You can find out more about units of alcohol at:  
[www.drinkaware.co.uk](http://www.drinkaware.co.uk)

Advice can vary, and some rheumatologists may suggest stricter limits. If you're concerned you should discuss your alcohol intake with your rheumatology team.

## Fertility, pregnancy and breastfeeding

You shouldn't take mycophenolate while you're trying for a baby, pregnant or breastfeeding. It does not affect your fertility, but it can affect your unborn child.

Your doctor may discuss your future plans for a family before prescribing mycophenolate. Whether you're a man or woman, you'll be advised to use one, if not two, methods of contraception while you're being treated with mycophenolate.

If you want to try for a baby, you should talk to your doctor first before you stop using contraception.



Women are advised to wait six weeks after stopping treatment before trying to conceive. Men are advised to wait 13 weeks before they stop using contraception. This allows the drug to fully leave your system.

If you're taking mycophenolate and you think you or your partner may be pregnant, contact your doctor immediately, they will be able to advise you on the best course of action.

If there's a possibility you may be pregnant, take a pregnancy test before starting mycophenolate.

You shouldn't breastfeed if you're on mycophenolate, as the drug may pass into your breastmilk. This could be harmful to your baby.

This leaflet is a guide to mycophenolate, its benefits and potential side effects. If there's anything else you'd like to know about this drug, just ask the healthcare professionals in charge of your care.

## Thank you!

A team of people helped us create this booklet. We would like to thank Dr Roshni Karia, Dr Neha Sahay, Dr Nick Wilkinson and Dr Elaine Morrison for helping us with reviewing this booklet.

We would also like to give a special thank you to the people who shared their opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.





**FAMILIES**  
**FRIENDS**  
**DOCTORS**  
**RESEARCHERS**  
**DONORS**  
**FUNDRAISERS**  
**VOLUNTEERS**  
**VERSUS**  
**ARTHRITIS**

Registered Charity No 207711  
Scotland No SC041156  
© Versus Arthritis 2019

**Versus Arthritis**

Copeman House  
St Mary's Court  
St Mary's Gate  
Chesterfield S41 7TD

Tel 0300 790 0400  
calls charged at standard rate

[www.versusarthritis.org](http://www.versusarthritis.org)  
[enquiries@versusarthritis.org](mailto:enquiries@versusarthritis.org)

Follow us:



VA2266