

Diagnostic and Advisory Service for Neuromyelitis Optica

Patient Information Leaflet

This information leaflet is designed to answer common questions patients ask about Mycophenolate. Further information can be found in the information leaflet supplied by the manufacturer or from your pharmacist or doctor.

MYCOPHENOLATE

What is Mycophenolate?

Mycophenolate mofetil (CellCept) reduces the activity of the body's immune system (the body's own defence system) so it is always used with care. Mycophenolate is used in the treatment of several different types of rheumatic disease, including systemic lupus erythematosus (SLE) and diseases in which there is inflammation of blood vessels ('vasculitis'). It may also be used after organ transplantation, for example in kidney transplants.

How long does it take to work?

Mycophenolate does not work immediately it can take up to 8 - 12 weeks before you have any benefit. It is important to continue treatment during this time. Mycophenolate cannot cure the condition and you may need to take it for several years to keep your relapses under control.

What dose do I take?

Mycophenolate is usually taken in capsule form twice a day. The dose is 500mg twice a day, increased in increments of 500mg every week up to 1g twice a day. The capsules should be taken with a glass of water or with food. Do not crush or chew the capsules. They should be swallowed whole.

Your doctor will advise you about the correct dose and may be changed depending on your response to the medication.

What are the common side effects?

The most common side-effects of Mycophenolate are sickness, diarrhoea, vomiting or abdominal (stomach) pain. Mycophenolate can also affect your blood count (one of the effects is that fewer blood cells are made) and can make you more likely to develop infections. If you develop a sore throat or other infection, a fever, unexplained bruising or bleeding, or if you develop any other unexpected new symptoms after starting mycophenolate, you should tell your doctor or nurse

specialist straight away. If any of these symptoms are severe, you should stop mycophenolate and see your doctor immediately.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should stop mycophenolate and see your doctor immediately as you may need special treatment. This is because chickenpox and shingles can be severe in people on treatment such as mycophenolate which has effects on the immune system. Therefore you may require antiviral treatment.

There is a slightly increased risk of certain types of cancer with mycophenolate. Discuss this with your doctor. Because of the small increase in risk of skin cancer, you should avoid exposure to strong sunlight and protect your skin with sunblock or sunscreen.

Rarely, people may be allergic to mycophenolate. If this is the case with you, the drug will have to be stopped. Symptoms of allergy include rash, wheezing, shortness of breath, and swelling of the face, lips, tongue or throat.

Do I need any special checks while on Mycophenolate?

Because mycophenolate can affect the blood count, and can sometimes cause liver or kidney problems, your doctor will arrange for you to have a blood test before you start treatment

It is important to have your blood checked regularly to check for early signs of changes in the blood. These blood tests show if the medication is working to control the inflammation or if you are developing any side effects. We recommend;

- full blood count including platelets,
- urea and electrolytes
- liver function tests

Initially done every week for 6 weeks,
monthly for 6 months and then at 2-3 monthly intervals.

The blood tests can be done at the clinic or, with agreement of your GP, at your local surgery. You may be asked to keep a record booklet with your blood test results. Bring this with you when you visit your GP or the hospital.

You should also show it to your dentist if you are having any dental treatment and to your pharmacist when collecting any prescriptions for you.

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 or malaise, contact your nurse, doctor, or pharmacist

If you are in close contact with anyone who has chicken pox or shingles inform your doctor or nurse specialist as soon as possible.

Can I take other medicines along with Mycophenolate?

Mycophenolate may be prescribed along with other drugs in treating your condition. Some drugs interact with mycophenolate, so you should discuss any new medications with your doctor before starting them, and you should always tell any other doctor treating you that you are taking mycophenolate.

Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

Vaccinations

It is recommended that you should not be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example rubella immunisation in women of childbearing age), in which case your doctor will discuss the possible risks and benefits of the immunisation with you.

Pneumovax and yearly flu vaccines are safe and recommended.

Alcohol

It is safe to drink alcohol in moderation whilst on mycophenolate, but it may aggravate liver problems.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Mycophenolate therapy. Make sure you take the monitoring booklet with you to all appointments and pre-assessment clinics. If you do need an operation, in most cases you will be advised to continue taking the Mycophenolate.

Is mycophenolate OK in pregnancy and breastfeeding?

You should not take mycophenolate when pregnant, and you should not become pregnant for at least 6 weeks after stopping mycophenolate. If you are planning a family or if you become pregnant while taking mycophenolate, you should discuss this with your doctor as soon as possible.

You should not breastfeed while taking mycophenolate. The drug could pass into the breast milk and the risk to the baby is unknown.

Never give any medications prescribed for you to anyone else