

Patient information factsheet

Mycophenolate to treat myasthenia

This factsheet contains information about the use of mycophenolate to treat myasthenia, including how the treatment is given and the possible side effects. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to your consultant neurologist, specialist nurse or pharmacist.

What is mycophenolate?

Mycophenolate is an immunosuppressant drug (a drug that damps down the immune system) that is used to control the body's immune system in conditions where it is overactive and causing harm (autoimmune diseases). Although mycophenolate is not licensed for use in neurological diseases, it is widely used to treat autoimmune diseases such as myasthenia gravis.

Mycophenolate can be prescribed on its own or it can be used in combination with steroid tablets. It is often referred to as a steroid-sparing agent, as it allows the dose of steroids to be kept to a minimum and reduces their side effects.

How is mycophenolate given?

Mycophenolate is taken by mouth in the form of tablets. The tablets should be swallowed whole and not chewed or crushed.

How often should I take mycophenolate?

Mycophenolate needs to be taken twice a day.

What dose should I take?

Your doctor will prescribe the most appropriate dose for you. This dose will be based on the results from your blood tests (before and during your treatment).

What should I do if I miss a dose?

If you miss a dose, do not worry. If more than six hours have passed from the usual time you take your dose, then miss that dose and take the next dose at your normal time. **Do not double up the dose.**

How long will I need to take mycophenolate for?

The length of time you will need to take mycophenolate for will depend on your condition. However, most people take mycophenolate for a few years. This is because it takes a little while (usually around six months to a year) to see the effects of the treatment.

Do not stop taking your medication (unless your doctor tells you to).

What are the possible side effects?

Most people who take mycophenolate have no side effects. However, some people may experience:

- sickness
- diarrhoea
- stomach pain
- a low white blood cell count (this increases your risk of infection)
- a low platelet count (this increases your risk of bruising and bleeding)
- an effect on their liver function

Contact your doctor immediately if you experience any of the following symptoms:

- flu-like symptoms
- a rash
- bruising
- bleeding

Increased risk of infection

As mycophenolate affects the immune system, it can make you more likely to develop infections. You should contact your doctor straight away if you come into contact with someone who has chickenpox or shingles (especially if you have not had chickenpox before). These infections can be more severe in people on mycophenolate and you may need special preventative treatment.

You should not have any 'live' vaccines while you are on mycophenolate, as this may cause an infection. Please discuss vaccinations with your doctor, as some are safe to have, such as the Pneumovax and yearly flu vaccines.

Increased risk of cancer

Mycophenolate may slightly increase your risk of developing some types of cancer, including skin cancer. For this reason, it is important that you avoid being exposed to strong sunlight and that you protect your skin with a sun cream that has a high sun protection factor (SPF of at least 30).

How will I be monitored for side effects?

For the first six weeks after starting mycophenolate, you will need to have fortnightly blood tests, so your doctor can check your blood count and liver function. After that, blood tests will be less often, falling to a minimum of once every three months while you take mycophenolate.

Your doctor may temporarily stop your treatment if your:

- white blood cell count drops too low
- platelet count drops too low
- number of red blood cells drops too low (you become anaemic)
- liver function is affected

Can I take mycophenolate if I am pregnant or breastfeeding?

You should not take mycophenolate if you are pregnant, could be pregnant, trying to become pregnant or breastfeeding. It is also important that you do not become pregnant for at least six weeks after stopping mycophenolate.

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Can I take other medications at the same time as mycophenolate?

It is important that you tell your doctor what medications you are taking (including non-prescription and herbal therapies) before starting mycophenolate. This is because some medicines interact with mycophenolate, including phenytoin, antacids, clozapine and some anti-viral drugs.

For more information about mycophenolate, please read the patient information leaflet that comes in the box with your tablets.

Contact us

If you have any questions or concerns, please contact us.

Myasthenia specialist nurse

Telephone: **023 8120 5948**

Useful links

www.emc.medicines.org.uk

www.nhs.uk/conditions/myasthenia-gravis

www.myaware.org/mycophenolate-information-sheet

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