

University College London Hospitals   
NHS Foundation Trust

# National Hospital of Neurology and Neurosurgery

## Queen Square Centre for Neuromuscular Diseases

Patient information leaflet:  
**Mycophenolate**



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## Introduction

This booklet discusses the use of mycophenolate in inflammatory neuromuscular diseases: what is it, why is it used, how is it taken, the aims and possible side effects related to its use.

The Queen Square Centre for Neuromuscular diseases have produced this leaflet as part of a guideline for patients and healthcare staff on the safe and appropriate use of medication which suppresses the immune system in inflammatory neuromuscular diseases. Content is reviewed and updated every 2 years by Dr Aisling Carr, consultant neurologist.

## What is mycophenolate?

Mycophenolate should help treat your condition. It has been in use for many years and has helped many people. However, as with all drugs some people will have side-effects.

Mycophenolate reduces the activity of the body's defence mechanism (immune system), which may be overactive in some conditions. It modifies the underlying disease process to limit or prevent tissue damage and disability, rather than having an immediate effect on symptoms.

Mycophenolate is a long-term treatment, so it may be 6-12 weeks before you start to notice the benefits. Unless you have severe side-effects it is important to keep taking mycophenolate: even if it doesn't seem to be working at first and even when your symptoms improve (as this will help to keep the disease under control).

## Why is it used?

Mycophenolate helps to achieve long-term control of symptoms due to inflammation in various neuromuscular conditions, such as:

- Myasthenia Gravis
- Inflammatory muscle diseases or myositis (dermatomyositis, polymyositis, overlap myositis)
- Vasculitis
- Other rheumatological and medical conditions like rheumatoid arthritis, lupus (SLE), asthma, allergy, Crohn's Disease, eczema
- To prevent organ rejection after transplantation

## What are the possible side effects?

As with all medications, mycophenolate can sometimes cause side effects such as:

- nausea (feeling sick), vomiting, diarrhoea, stomach pain.

It can also affect the blood (causing fewer blood cells to be made), the liver or the kidneys. You will therefore need to have blood tests before starting mycophenolate and at regular intervals while you're taking it. You will have your bloods taken by your GP or at the hospital. The neuromuscular clinical nurse specialist will keep a record of your results.

### **YOU MUST NOT TAKE MYCOPHENOLATE UNLESS YOU'RE HAVING REGULAR BLOOD CHECKS.**

Although this is uncommon, there's a slightly increased risk of certain types of cancer in people using mycophenolate. Please discuss this matter with your doctor if you're worried. 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.

### **Is infection a side-effect of mycophenolate treatment?**

Yes. Because mycophenolate affects the immune system, it can make you more likely to develop infections. Try to avoid close contact with people with severe active infections. For advice on avoiding infection from food, visit:

<http://www.nhs.uk/conditions/food-poisoning/pages/prevention.aspx>

You should tell your doctor or nurse specialist straight away if you develop any of the following after starting mycophenolate:

- a sore throat,
- fever or any other signs of infection,
- unexplained bruising or bleeding,
- yellowing of the skin or eyes (jaundice),
- any other new symptoms or anything else that concerns you.

You should stop mycophenolate and see your doctor immediately if any of these symptoms are severe or if you become very unwell. In rare cases, mycophenolate causes inflammation of the lung with breathlessness. If this happens to you, see your doctor.

You should also see your doctor if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. These infections can be severe in people on mycophenolate. You may need antiviral treatment, and you may be advised to stop taking azathioprine until you're better.

### **What vaccinations should I get?**

It's usually recommended that you avoid live vaccines, such as yellow fever, if you're on mycophenolate. However, sometimes a live vaccine may be necessary – for example, rubella vaccination in women of childbearing age. If you're offered shingles vaccination (Zostavax), you should speak to your neurology team – you may be able to have the shingles vaccine if you're on a low dose.

Pneumococcal vaccine (which gives protection against the commonest cause of pneumonia) and yearly flu vaccines are recommended

### **Is there an alternative?**

There are a number of alternatives to mycophenolate with a range of different side-effects. Drugs such as azathioprine and methotrexate have a similar effect on the immune system as mycophenolate and are considered when mycophenolate is not well tolerated.

If your disease is not fully controlled by mycophenolate then stronger medications, such as cyclophosphamide might be suggested. We have produced patient information leaflets on all these medications.

### **What will happen if I choose not to take it?**

The medical team will explain the alternatives and the typical outcome in people with your condition if treated or left untreated. If they are happy that you fully understand the implications of your decision your choice will be respected.

### **How do I take it?**

It is given as a capsule or as a tablet depending on the dose required, and is usually taken twice a day with food or water. They should be swallowed whole and not crushed or chewed. Your doctor will advise you about the correct dose. Higher doses are usually taken as tablets rather than capsules.

Unless you have severe side-effects it's important to keep taking mycophenolate:

- even if it doesn't seem to be working at first
- even when your symptoms improve (as it will help to keep the disease under control).

### Can I take other medications with mycophenolate?

Some drugs can interact with mycophenolate. Check with your doctor or pharmacist before starting any new medications, and remember to mention you're on mycophenolate if you're treated by anyone other than your neurology team.

- Don't take over-the-counter preparations or **herbal remedies** without discussing this first with your healthcare team.

### Can I drink alcohol while taking mycophenolate?

You should only drink alcohol in small amounts because alcohol and azathioprine can both affect your liver. It's important not to drink more alcohol than the government recommended safe limits – these state that adults shouldn't drink more than 14 units per week. It's also strongly recommended to have alcohol free days without 'saving units up' to drink all in one go. If you're concerned you should discuss your alcohol intake with your neurology team.

### Is mycophenolate safe in pregnancy and breastfeeding?

You shouldn't take mycophenolate when pregnant, and you shouldn't become pregnant for at least six weeks after stopping it. If there's a possibility you may be pregnant **you should have a pregnancy test before starting mycophenolate**.

If you're planning a family or if you become pregnant while taking mycophenolate, you should discuss this with your doctor as soon as possible.

You shouldn't breastfeed if you're on mycophenolate. The drug may pass into the breast milk and could be harmful to your baby.

## References

K Chackravaty et al., **BSR/BHPR guideline for disease-modifying anti-rheumatic drug (DMARD) therapy in consultation with the British Association of Dermatologists**. Rheumatology 2008; 1-16.

## Contact details

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**Website:** <http://www.cnmd.ac.uk/>

## Where can I get more information?

[www.wikipedia.org/wiki/azathioprine](http://www.wikipedia.org/wiki/azathioprine)

[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

Any azathioprine document at [www.medicines.org.uk](http://www.medicines.org.uk)

For further detail please also see the relevant Summaries of Product Characteristics (SPC) document at [www.medicines.org.uk](http://www.medicines.org.uk)

Guillain-Barré & Associated Inflammatory Neuropathies Charity

Tel: 01529469910

<http://www.gaincharity.org.uk/>

British Rheumatological society: Patient information

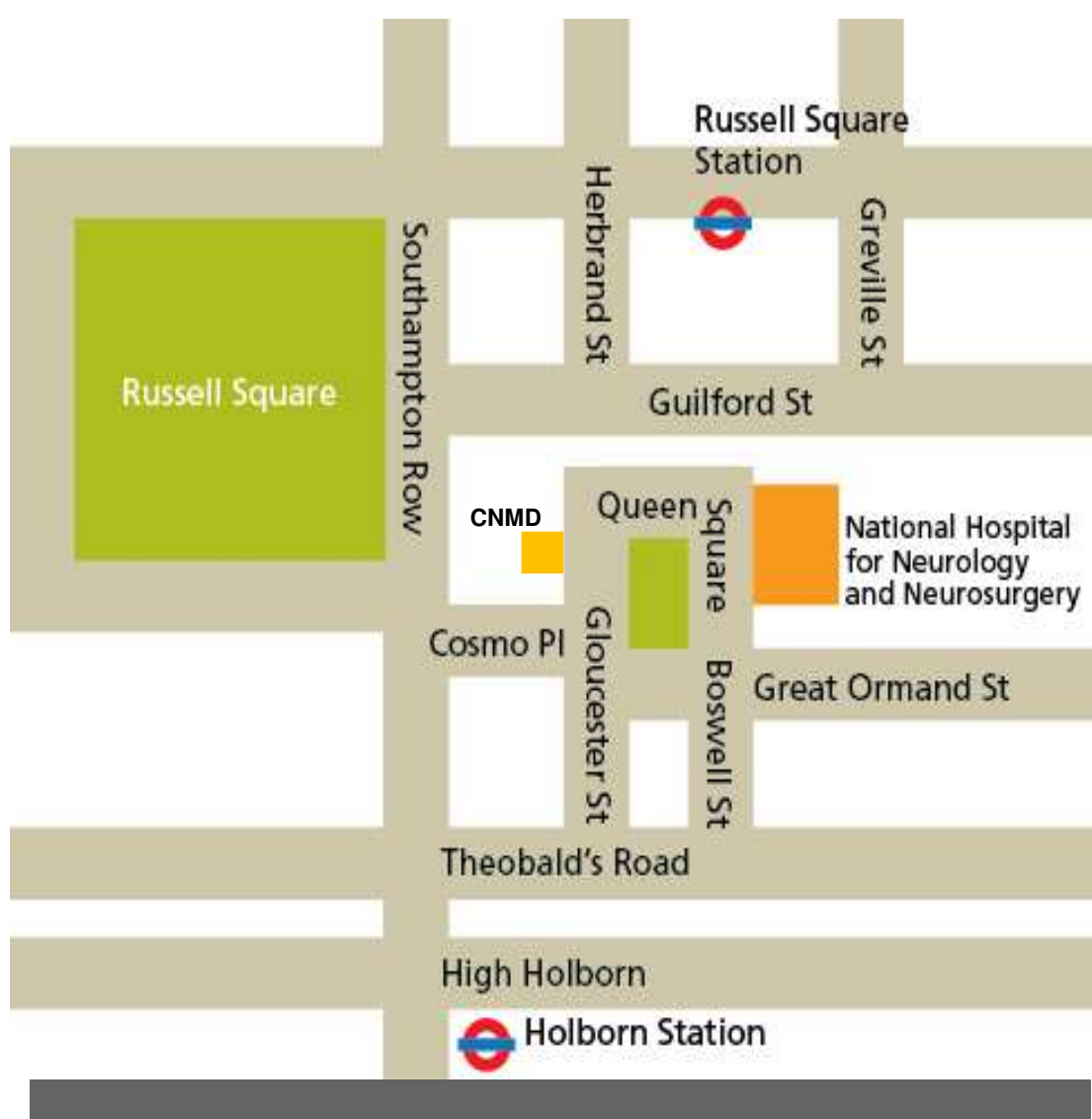
Tel: +44 (0) 20 7842 0900

<http://www.rheumatology.org.uk>

UCLH cannot accept responsibility for information provided by external organisations.

### How to find us

Neuromuscular outpatient clinics run across the hospital outpatient departments, please see your appointment letter for further information. The Centre for neuromuscular diseases (CNMD) is based on the ground floor of 8-11 Queen Square, directly across from the main hospital entrance.





## Space for notes and questions

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