



Living with pulmonary fibrosis: Immunosuppressant medications

Mycophenolate (Cellcept, Myfortic)



Disclaimer

This resource provides some information about the immunosuppressant medication mycophenolate. It does not contain all the available information and **does not take the place of talking to your doctor or pharmacist**. Always seek the guidance of your doctor or other qualified health professional for any questions you may have regarding medications, your health or medical conditions. Please refer to the Consumer Medicine Information leaflet linked below for a more detailed guide to side effects and safety precautions.

Why is this medication being recommended?

Mycophenolate belongs to a group of medications known as immunosuppressants. These medications help control your body's immune system and reduce inflammation in your lungs.

Inflammation may lead to fibrosis (scarring) in the lungs. By reducing inflammation, mycophenolate may prevent the formation of more lung fibrosis, and, in some cases may allow the inflamed lung to return to normal.

When starting mycophenolate, your doctor will tell you how much to take and when to take it. Usually, the medication is taken twice a day, about 12 hours apart and the dose is often increased over a few months until you reach the right dose for you. You will need to have regular blood tests, usually monthly to start and then every three to four months. Your doctor might change the dose if necessary.

What special precautions should I follow?

Before taking mycophenolate:

- Tell your doctor and pharmacist if you are allergic to mycophenolate, mycophenolic acid, any other medications, foods, preservatives or dyes.
- Tell your doctor and pharmacist if you are taking other prescription and non-prescription medications, vitamins, nutritional supplements, and herbal products. Your doctor may need to change the dose of your medications or monitor you carefully for side effects.
- Mycophenolate is not recommended for pregnant women. Tell your doctor if you are pregnant or breastfeeding, or if you or your partner plan to become pregnant.
- Talk to your doctor about effective methods of contraception if you or your partner could become pregnant.
- Tell your doctor if you currently have or previously had any other health problems, in particular sunspots or skin cancer, low white blood cell count, stomach or bowel problems, rare inherited diseases and liver or kidney disease.

While taking mycophenolate:

- Avoid infection by staying away from people who have easily transmitted infections and washing or sanitising your hands often.

- Vaccinations are important. Discuss vaccination schedules with your doctor while on mycophenolate and always check before receiving a vaccine.
- If you are taking antacids, take them 2 hours before or 4 hours after mycophenolate.
- Neurological side effects are rare - tell your doctor if you experience vision problems, loss of coordination, tremor or memory loss.
- Be careful driving and operating machinery until you know how mycophenolate affects you.
- Tell any other doctors, dentists and pharmacists who treat you that you are taking mycophenolate and remind them of this if you are about to be started on any other new medication.
- If you are having surgery, including dental surgery, tell the doctor or dentist that you are taking mycophenolate.
- Avoid pregnancy or planning a pregnancy. Use effective contraception during treatment and for three months after treatment if you or your partner could become pregnant. If you become pregnant, tell your doctor immediately.
- Do not breastfeed while you are taking this medication.
- Be sun smart - wear a long sleeve shirt, hat and SPF 50 sunscreen while in the sun to reduce the risk of skin cancers.

What side effects can this medication cause?

Immune suppressing medications can decrease your ability to fight infection. You need to be alert to the signs of infection and see your doctor immediately if you are concerned:

- Be alert for fever (particularly above 38 degrees Celsius), chills, lethargy or other signs of infection.

Mycophenolate may cause other side effects. Tell your doctor if any of these symptoms are severe or do not go away:

- Diarrhoea, stomach pain, upset stomach, nausea and vomiting are some of the most common side effects with mycophenolate
- Muscle or joint pain
- Skin rashes
- Difficulty falling asleep or staying asleep

- Headache
- Blood test abnormalities including low blood cell counts and abnormal liver function tests. Regular blood tests are recommended to monitor for this.

Some side effects can be serious. The following symptoms are uncommon, but if you experience any of these, contact your doctor immediately:

- Difficulty breathing or chest pain
- Unusual bruising or bleeding
- Skin lesions
- Excessive tiredness, dizziness, pale skin, weakness
- Black and tarry stools, red blood in stools, bloody vomit
- Symptoms of infection (e.g. new productive cough) and high fevers.

What monitoring will I need?

Your GP or lung specialist will order regular blood tests to monitor for side effects. These will include blood counts (white blood cells, red blood cells, platelets) and liver tests. There may be additional tests ordered by your doctor depending on the results.

Your specialist will also review you to discuss any other side effects you may be experiencing. They will also continue to monitor your lung function (breathing tests) over time to map out the progress of your lung condition. It's helpful to keep your own detailed record of your prescriptions and tests.

Notes on your mycophenolate prescription:

	Mycophenolate dose	Blood test (Yes/No/Date)	Side effects and other notes
Month 1			
Month 2			
Month 3			

FURTHER INFORMATION AND SUPPORT

Lung Foundation Australia Services

- Information and Support Team
- Lung disease information resources
- Education webinars
- Support groups
- Peer-to-peer connections
- Referral to pulmonary rehabilitation and Lungs in Action exercise programs

External Links

- Mycophenolate (Cellcept) Consumer Medicine Information leaflet: [tga.gov.au](https://www.tga.gov.au)
- Mycophenolate (Myfortic) Consumer Medicine Information leaflet: [tga.gov.au](https://www.tga.gov.au)

[Lungfoundation.com.au](https://lungfoundation.com.au) | Freecall 1800 654 301 | enquiries@lungfoundation.com.au

We thank the individuals and teams who contributed to the content and expert review of this fact sheet, in particular, the Interstitial Lung Disease Clinic team at Royal Prince Alfred Hospital and Darling Downs Respiratory and Sleep Clinic team.

Note to reader: This information is intended as a general guide only and is not intended or implied to be a substitute for professional medical advice or treatment. While all care is taken to ensure accuracy at the time of publication, Lung Foundation Australia, the Centre of Research Excellence in Pulmonary Fibrosis and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided. Always consult with your doctor about matters that affect your health.

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