



**University
Hospitals Sussex**
NHS Foundation Trust

Mycophenolate in autoimmune hepatitis

Pharmacy

Patient information

What is this information about?

This information is about a drug called mycophenolate which is used to treat autoimmune hepatitis, also known as AIH. AIH is usually a lifelong liver condition. It is an autoimmune disorder which means your body's immune system (the body's defence against illness) attacks your body's own cells.

This information tells you about how and when to take mycophenolate; what happens before you take mycophenolate; things that should be aware of while you are taking it; possible risks and side-effects. It also tells you how the specialist liver team will look after you while you take it, and how to contact them should you need to.

What is mycophenolate?

Mycophenolate is a medication that is used to treat different medical conditions including AIH. Mycophenolate slows down or moderates your body's over-active immune system to treat the inflammation.

How long does mycophenolate take to work?

Mycophenolate can take 6 to 12 weeks before the full effect is seen.

What will happen before I start mycophenolate?

You will need several blood tests to make sure it is safe for you to start the medication. These may include:

- tests to check your full blood count
- liver and kidney function and tests for viral infections, including:
 - cytomegalovirus (CMV).
 - Epstein-Barr virus (EBV).
 - hepatitis B and C.
 - HIV.
 - varicella (chickenpox and related viral infections).

What vaccinations are recommended while I am taking mycophenolate?

Unless there is a medical reason that you cannot have them, we recommend that you have the following:

- the flu vaccine (every year).
- the vaccine against strains of pneumonia.
- the Covid vaccine (as per current national schedule).

If you are over 50 years old and have had prednisolone at 10mg or more a day for more than four weeks in the past three months, we recommend that you join the non-live shingles (Shingrix) vaccine programme. Your GP practice can arrange this for you.

If you need vaccinations for travel, check with your specialist liver team first.

You should not have live vaccines while on mycophenolate, and for three months after stopping it. If you have been recommended to have a live vaccine or if you are not sure if a vaccine is live, please contact the specialist team (details below).

How do I take mycophenolate?

- Mycophenolate is available as 250mg and 500mg strength tablets or capsules. The generic (non-branded) version is usually prescribed.
- It is important you take your mycophenolate regularly and approximately the same time, or times, each day.
- It is usually taken twice a day, 12 hours apart.
- Do not take the tablet or capsule out of the foil strip until you are ready to take it.
- Swallow the tablet or capsule whole with water.

Be aware

Stopping mycophenolate will increase the risk of an autoimmune flare. Do not stop taking mycophenolate unless your specialist team tells you to.

How long will I be taking mycophenolate?

The length of treatment depends on each person. It is likely to be for several years and longer. Some people take it all their lives.

Can I stop taking mycophenolate at any time?

No. Stopping mycophenolate will increase the chance of an autoimmune flare. Do not stop taking mycophenolate unless your specialist team tells you to.

If you are concerned about side effects, please contact your specialist team (details below).

Does mycophenolate interfere with other medicines?

Mycophenolate can interfere with other medicines. Please let your healthcare teams know about all the medicines that you are taking, including:

- anything prescribed for you.
- any medicines you bought from a pharmacy or shop.
- alternative (herbal, homeopathic) medicines that you buy yourself.
- before you start treatment with mycophenolate.

When you have started treatment, you should always check with your doctor or pharmacist before starting any new medicines.

Can I drink alcohol while taking mycophenolate?

Any amount of alcohol can damage the liver, especially if you have an underlying condition such as AIH.

Your specialist team may ask you to avoid alcohol completely.

If you are allowed to drink alcohol, it is recommended that you keep well within the national recommended limits of alcohol consumption. This is a maximum of 14 units per week. Please see **Alcoholic drinks and units / Drinkaware** for more information <https://www.drinkaware.co.uk/facts/information-about-alcohol/alcoholic-drinks-and-units/>. Any amount of alcohol can damage the liver, especially if you have an underlying condition such as autoimmune hepatitis.

What if I forget to take a dose?

As this is taken twice per day, you have six hours to take the medication.

If you realise you have missed it after six hours has passed, wait and take the next dose as usual. Do not take a double dose to catch up.

It is very important you take your mycophenolate regularly and at about the same times each day. If you miss a lot of doses, the chance of your auto-immune condition flaring up will be higher.

What if I take too many tablets or capsules?

Get help immediately:

- From your specialist team, Monday to Friday, 9am to 4pm. Contact details are below.
- Outside of these hours, please contact **NHS 111**, an out of hours GP, or attend an emergency department (A&E) if you are very unwell.

Is mycophenolate safe in pregnancy and breastfeeding?

No. Mycophenolate is not recommended in pregnancy due to the potential risk to the unborn child.

Women

Women of childbearing age must be using TWO forms of highly effective contraception before starting mycophenolate, while taking mycophenolate, and for six weeks after stopping mycophenolate.

Please tell the specialist team if you are considering having a baby. If you become pregnant while taking mycophenolate please inform the specialist team as soon as possible.

Men

Use condoms if you have sex while you are taking mycophenolate, even if you have had a vasectomy, and for at least 90 days after stopping treatment, as it can affect your sperm.

Female partners of male patients treated with mycophenolate should use highly effective contraception during treatment and for 90 days after the last dose.

Please discuss any family planning with your specialist team.

Are there any side effects to mycophenolate?

Contact a healthcare professional if you experience or have any concerns about side effects.

You can contact your specialist team during regular working hours Monday to Friday 9am to 4pm (see below for contact details).

For information outside of these hours or in cases of emergency please contact **NHS 111**, an out of hours GP, or attend an emergency department (A&E) if you are very unwell.

Infection: Mycophenolate works by slowing down or moderating your body's over-active immune system. You may be more likely to get an infection or take longer to recover from infections.

Contact your GP (or out-of-hours medical advice) as soon as possible

if you begin to feel unwell and think you might have caught an infection. This includes signs of fever, a sore throat or cough.

Listed common side effects:

- Hair loss.
- Stomach upsets.
- Your blood count may be affected.
- Sleep disturbance.
- Tiredness.
- Headaches.
- Changes in your blood pressure.
- Tremor (shaking or trembling).
- Weight changes.
- Increased risk of developing cancer (particularly of the skin).

Mycophenolate can increase risk of sunburning, and so national advice on sun safety should be followed:

- seek shade from 11am to 3pm.
- never burn, cover with suitable clothing and sunglasses.
- use high sun protection factor (at least 30).
- regularly check your skin for changes (for example, new moles or mole changes).

What monitoring do I need while I am on mycophenolate?

We will monitor your blood tests to make sure that the mycophenolate is working correctly and not affecting your bloods. It is important you do your bloods when you are asked to. This will help to keep you safe.

Your specialist team will let you know what bloods are needed and when. At the beginning they are usually every two weeks for at least six weeks. Once they are stable, they could move to every three months.

How do I get a repeat prescription?

At the start of taking mycophenolate, the hospital will supply it.

Once you are stable on the medication, the hospital may be able to arrange that you can get this medication via your GP. If this is not possible then the hospital will continue to supply it.

If you are running out between appointments then please email the gastroenterology pharmacy team. Their contact details are below.

Where can I find more information?

More information about AIH can be found:

AIH Support <https://aihsupport.org.uk/about-aih/>

British Liver Trust

<https://britishlivertrust.org.uk/information-and-support/liver-conditions/autoimmune-hepatitis/>

How do I contact the specialist liver team or gastroenterology pharmacy team?

If you have any questions or concerns about your AIH, please contact the specialist liver team at: uhsussex.digestivediseasesmedsecs@nhs.net

If you have questions about your liver medication (including repeat prescriptions), contact the gastroenterology pharmacy team at: uhsussex.gastro.pharmacy.brighton@nhs.net

This information is intended for patients receiving care in Brighton & Hove, Chichester, Worthing and Haywards Heath hospitals.

Ref. number: 2393
Publication date: 08/2023
Review date: 08/2026

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