

Mycophenolate for the treatment of autoimmune liver disease

Information for patients

This leaflet contains information about mycophenolate, which is a medication that can be used to treat autoimmune liver disease, a condition in which your body's immune system attacks your liver. If you have any other questions or concerns, please do not hesitate to speak to the doctors, nurses or pharmacists caring for you.

What is mycophenolate?

Mycophenolate is a drug used to suppress the immune system. It is used to treat autoimmune conditions, such as autoimmune hepatitis and autoimmune sclerosing cholangitis by reducing or preventing inflammation of the liver. Mycophenolate helps to prevent flare-ups and helps to control or reduce symptoms.

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 some blood tests to make sure it is safe for you to start taking the medication. These may include:

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

How do I take mycophenolate?

- Mycophenolate is available as 250mg and 500mg strength tablets or capsules. The generic (non-branded) version is usually prescribed.
- The dose is usually taken twice a day (morning and evening).
- It is important that you take your mycophenolate regularly and approximately at the same times each day.
- Do not take the tablet or capsule out of the foil strip until you are ready to take it.

- You should take each dose with or immediately after food to help reduce stomach upset.
- Swallow the tablet or capsule whole with water.

How long will I take mycophenolate?

The length of treatment depends on each person. It is likely to be for several years or 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).

What should I do if I forget to take a dose?

As this is taken twice per day, you have 12 hours to take the medication. If you forget to take a dose, and it is within six hours of when the dose was due, take it as soon as you remember. If you realise you have missed it after six hours has passed, wait until the next dose is due. Do not take a double dose.

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 autoimmune 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 5:30pm.
- 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.

Should I take mycophenolate on the day that I have a clinic appointment?

On the day that you attend your clinic, please take your medications as prescribed. Monitoring of mycophenolate blood levels is not routinely performed.

Side effects of mycophenolate

Mycophenolate has several side-effects but not everyone will experience them. Some of the side-effects may resolve or improve if the dose, or timing of dose is adjusted.

Talk to a doctor or NHS 111 **immediately** if you experience any of the following:

- signs of an infection such as a sore throat, fever or cough
- unexpected bruising or bleeding
- rash, swelling of your face, tongue or throat, and/or difficulty breathing (you may be having a serious allergic reaction mycophenolate)
- jaundice (yellowing of eyes or skin)
- severe upper stomach pain

The most common side effects are:

- stomach upsets
- diarrhoea

- tiredness and difficulty sleeping
- pains (such as stomach, chest, joint or muscles)
- headaches
- changes in your blood pressure
- tremors (shaking or trembling)
- weight changes
- increased risk of developing cancer (particularly of the skin)
- your blood count may be affected

Mycophenolate can increase the risk of sunburning and skin cancer, 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 SPF 30)

Regularly check your skin for changes (for example, new moles or mole changes). You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution.

What monitoring do I need while I am on mycophenolate?

After starting mycophenolate, or after any dose changes, you will need blood tests every two weeks for at least six weeks, until your dose is stable. Once they are stable, they could move to every three to six months. Then, it can vary, but usually you need blood tests every three to six months. Your kidney function, liver function, full blood count and blood pressure will be monitored while you are on mycophenolate.

Taking other medicines with mycophenolate

Some medicines can interact with mycophenolate, altering how well it works. Always check with your liver doctor or pharmacist if you are prescribed new medications, or if you buy any new medicines over the counter, including herbal or complementary medicines. Some medicines can reduce the amount of mycophenolate absorbed by your body, or lower the levels in your blood, for examples some medicines for indigestion, and some antibiotics and antifungals.

Other medications such as antivirals (like aciclovir and ganciclovir), medicines that suppress your body's immune system (immunosuppressants) or medicines that can reduce your white blood cell count (such as clozapine) can also interact with mycophenolate.

Vaccines

Some vaccines contain a live form of the virus. These are called live vaccines. If you are taking mycophenolate, you cannot have live vaccines and for three months after stopping mycophenolate. If you are considering vaccinations check with your doctor or pharmacist first.

It is still important to get the following:

- Flu vaccine: recommended
- COVID-19 vaccine: recommended
- Pneumovax: recommended
- Shingles vaccine (Shingrix): make sure that you get the NON-LIVE formulation

Can I drink alcohol while taking mycophenolate?

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

Storage

Store your mycophenolate in a cool, dry place, away from direct sunlight. Keep the blister in the outer carton to protect from light. Keep your mycophenolate out of the sight and reach of children. Do not use after the expiry date on the packaging. Ask your pharmacist how to dispose of any medicines no longer needed.

Supply

At the start of taking mycophenolate, the hospital will supply it. You will be supplied with enough medication to last until your next clinic appointment. Once you are stable on the medication, the hospital may be able to arrange that you can get this medication through your GP. If this is not possible then the hospital will continue to supply it.

If you are running out of supply between appointments, please email the liver secretaries (contacts below) at least two weeks before you are due to run out of your mycophenolate to arrange a supply.

Is mycophenolate safe in pregnancy?

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

Please discuss any family planning with your specialist team and tell them if you are considering having a baby. If you become pregnant while taking mycophenolate please inform the specialist team as soon as possible.

Contraception

Women and those assigned female at birth who can have children must be using TWO forms of highly effective contraception before starting mycophenolate, while taking mycophenolate, and for six weeks after stopping mycophenolate.

Men (including those who have had a vasectomy) and those assigned male at birth must use condoms if having sex while taking mycophenolate, and for at least 90 days after stopping treatment as it can affect their sperm.

Women and those assigned female at birth who are having sex with men or those assigned male at birth who are taking mycophenolate should use highly effective contraception during treatment and for 90 days after the last dose.

Is mycophenolate safe in breastfeeding?

No. Do not breastfeed while taking mycophenolate.

Additional information

- If you take mycophenolate, you may be more at risk of getting infection.
- If you come into skin contact with someone with chickenpox or shingles, or if you develop chickenpox or shingles, you need to contact your doctor immediately.

- Do not take this medicine if you have a hypersensitivity to mycophenolate or mycophenoloic acid.
- Do not donate blood whilst on mycophenolate and for at least 6 weeks after your last dose.
- Men and those assigned male at birth must not donate semen during treatment with mycophenolate.

How can I find out more?

If you would like any more information on mycophenolate, or if you need to get in contact with a member of the liver team, please use the details below (available Monday to Friday, from 9am to 5.30pm).

- Liver Outpatients: kch-tr.liver.outpatients@nhs.net
- Liver Pharmacy Team: kch-tr.liverpharmacy@nhs.net

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. Visit www.kch.nhs.uk/mychart to find out more.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: 020 3299 4618

Email: kings.pals@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net