

Azathioprine for autoimmune hepatitis

The leaflet aims to answer your questions about taking azathioprine for autoimmune hepatitis (AIH). If you have any questions or concerns, please speak to a doctor, nurse or pharmacist caring for you.

What is azathioprine?

Azathioprine is used to treat a variety of medical conditions such as autoimmune hepatitis (known as AIH). With AIH the body's defences are overactive and cause inflammation in the liver. Azathioprine suppresses the body's immune system to treat the inflammation. Azathioprine acts slowly so it may be up to three months before its benefits are seen.

What will happen before I start the medication?

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 blood count, liver and kidney function, TPMT (to measure the amount of enzyme you have in your blood that breaks down azathioprine), and tests for hepatitis B and C, EBV (Epstein-Barr virus) HIV and varicella (chicken-pox).

Before you start the medication, it is strongly recommended that you have the vaccine against strains of pneumonia (pneumococcal). It is also recommended that you have the flu vaccine every year while on the medication. Your GP practice can arrange these for you.

How do I take the medicine?

The dose depends on your weight. Typically doses vary between 25mg and 200mg daily and may be changed during the course of your treatment. Azathioprine is routinely available as 25mg and 50mg tablets.

You should take each dose with or immediately after food to help reduce stomach upset. The medicine should be swallowed whole with a glass of water. Normally people take the medicine in the morning but taking it before going to bed can help if you are having problems with nausea (feeling sick). In most cases the full dose is taken all at the same time but in some cases we may recommend splitting the dose throughout the day.

How long will I be taking it?

The length of treatment depends on each person but it is likely to be for several years and longer in some cases.

Does azathioprine interfere with other medicines?

Azathioprine can interact with other medicines. Please let your doctor and healthcare team know about all of the medicines that you are taking, including anything prescribed for you and any over-the-counter or alternative (herbal, homeopathic) medicines that you buy yourself, before you start treatment with azathioprine. When you have started treatment, you should always check with your doctor or pharmacist before starting any new medicines.

A medicine used for the treatment of gout, called allopurinol, interacts with azathioprine so they should not usually be taken together. However, in some cases allopurinol will deliberately be prescribed by your specialist team, to be used with a low dose of azathioprine, if you are experiencing lots of side effects or abnormal blood tests with azathioprine.

Other medicines such as co-trimoxazole, trimethoprim and warfarin can also interact with azathioprine.

You should ideally avoid 'live' vaccines when you are taking azathioprine and for at least three months after stopping it. If you are considering vaccinations (for example, for travel) check with your doctor or pharmacist first.

Can I drink alcohol whilst taking azathioprine?

It is recommended that you keep well within the national recommended limits of alcohol consumption (maximum of 14 units per week). Please bear in mind any amount of alcohol can damage the liver, especially if you have an underlying condition such as autoimmune hepatitis. Depending on the state of your liver, your clinician may ask you to avoid alcohol completely

What should I do if I forget to take the medicine?

If you remember within 12 hours of your dose being due, take your dose as normal. If it is more than 12 hours, then take the next dose as planned. Do not double your dose if you have forgotten.

It is important that you try not to forget any doses. Azathioprine works slowly and therefore if you regularly forget the medication this will result in you having a lower level in your blood, potentially making it less effective.

Is azathioprine safe in pregnancy and breastfeeding?

The most important thing is that your AIH is as controlled as well as possible during pregnancy. It is important that you tell us if you are pregnant or planning on getting pregnant so that we can review all of your medicines and monitor you more closely. Our team will be able to discuss the risks and benefits of continuing azathioprine during pregnancy. Many patients continue to take azathioprine safely throughout their pregnancy.

Are there any side effects?

Azathioprine works by suppressing your immune system and therefore you may be more likely to get an infection. Contact your GP if you begin to feel unwell and think you might have caught an infection.

Everyone responds differently to the medication but possible side effects include:

- nausea, especially at the start of treatment. We may need to make changes to how and when you take the medication
- flu-like symptoms including headache, muscle ache, general malaise— these may develop at the beginning of treatment but they are not usually serious, and often go away within a few weeks
- headache
- diarrhoea
- dizziness
- hair loss (many cases resolve despite continued treatment)
- rashes —please contact a healthcare professional if you develop any signs of a rash after starting azathioprine

More serious side effects are listed below. These will require closer monitoring and in some cases, we may decide to stop the medication.

- The medication can suppress your bone marrow resulting in a reduction in the number of red cells, white cells and platelets produced. This will be monitored on your blood tests. It is important that you report any unexplained signs of bruising, bleeding or high fever
- Serious infection requiring medical treatment (such as antibiotics).
- Abnormal liver function tests can occur in about one in 20 people. These will be monitored on your blood tests but if you notice jaundice (yellowing of the eyes or skin) then please let us know immediately.
- Pancreatitis (inflammation of the pancreas) occurs in about one in 30 people. This normally causes severe upper abdominal (stomach) pain. If this occurs then please contact us immediately.
- Azathioprine increases the skin's sensitivity to the sun and so increases the risk of certain types of skin cancer. It is important to take precautions in the sun, such as wearing protective clothing and using a high sun protection factor (SPF 50) sun cream.
- Lymphoma is a type of cancer affecting the lymph glands. The risk of getting this is higher than in the general population but it remains very rare (one in 2500 people).

Contact a healthcare professional if you experience any of the above side effects, or if you have any concerns. Our contact details are at the end of this leaflet. If you need to speak to a healthcare professional outside of our regular working hours (Monday-Friday 9am-5pm), please contact NHS 111, an out of hours GP, or attend an emergency department (A&E) if you are very unwell.

Is there anything else I need to know?

- When you first start azathioprine, you will need regular blood tests every few weeks.
- If your blood tests are stable after three months of treatment then you could continue to have them checked every three months with your GP.
- When you first start the medication our specialist doctors and pharmacists will be monitoring you to assess for side effects or abnormalities on your blood tests. Please expect to have regular appointments or receive phone calls from them.
- We will also be monitoring the levels of azathioprine in your blood, and may adjust your dose depending on the results.
- It is important that all medications are kept out of the reach of children.

How do I get a repeat prescription?

- After your hospital specialist has started azathioprine, they will advise your GP what dose to prescribe. Your initial prescriptions will be issued by the hospital until your GP has agreed to take over prescribing. If your GP does not agree to prescribe your azathioprine, your prescriptions will continue to be supplied from our hospital
- If any changes to the dose are needed then the hospital will tell your GP.
- Monitoring blood tests are essential. If these are not done your prescription may be withheld until up-to-date blood tests are obtained.

Useful sources of information

For more information about autoimmune hepatitis please refer to the British Liver Trust website (britishlivertrust.org.uk).

Contact us

If you have any questions or concerns about azathioprine, please contact the hepatology team via the secretaries on **020 7188 2492**. Alternatively contact our Liver team via email LiverHelpline@gstt.nhs.uk. For enquiries specifically about your liver medication, contact pharmacy team via email gastropharmacist@gstt.nhs.uk.

Please leave your name, date of birth, hospital number and details of your enquiry. Queries will be responded to 9am to 5pm, Monday to Friday. If you are concerned outside these hours, please contact your GP or call NHS 111.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111 **w:** www.111.nhs.uk

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. **w:** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 5077/VER1

Date published: October 2020

Review date: October 2023

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A list of sources is available on request