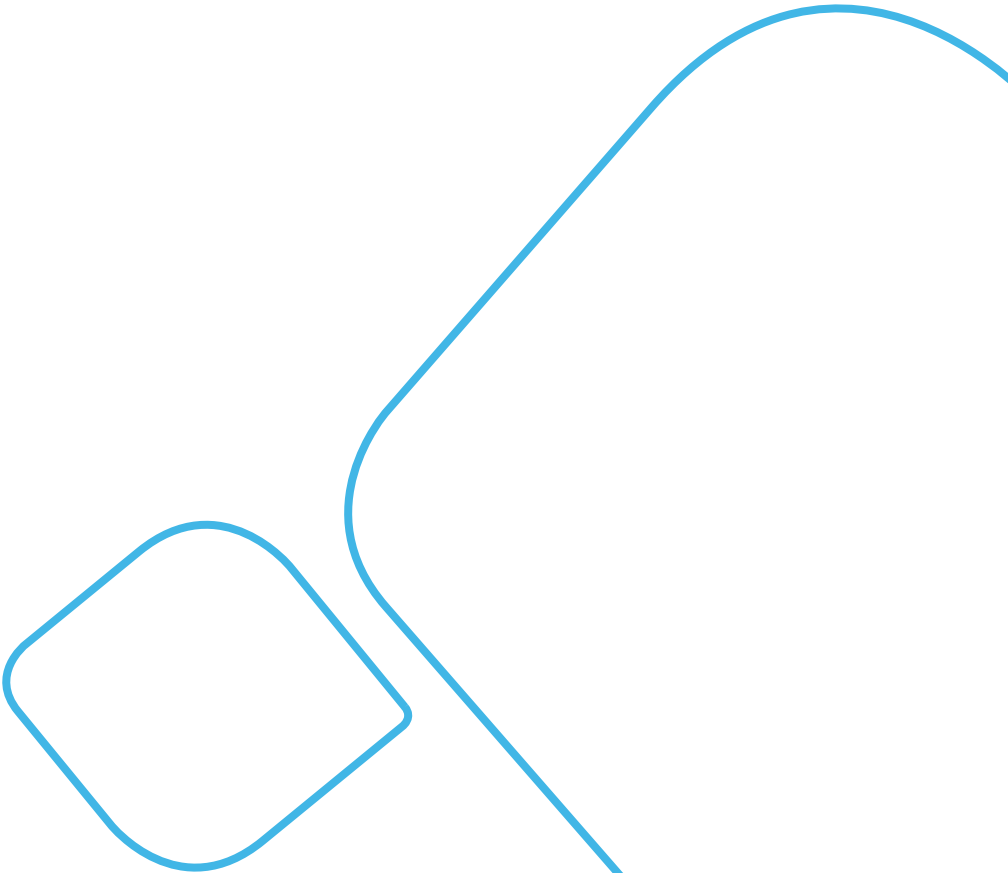


# Autoimmune Hepatitis

AIH

## Azathioprine & mercaptopurine



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**Autoimmune Hepatitis**, also known as AIH, is usually a lifelong liver condition. It is an autoimmune disorder in which your body's immune system (the body's defence against illness) attacks your own liver cells.


**Azathioprine & mercaptopurine** are part of a group of medications called thiopurines which help to treat this condition.

**What are thiopurines?** Thiopurines are used to treat a variety of medical conditions including AIH. They control your body's over-active immune system to treat the inflammation. Thiopurines can act slowly so it may be up to three months before its benefits are seen.

**What will happen before I start thiopurines?** 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, Thiopurine methyltransferase (TPMT) to measure how well your body will clear the medication from your system and tests for viral infections including cytomegalovirus (CMV), Epstein-Barr virus (EBV), hepatitis B and C, HIV and varicella (chickenpox and related viral infections).

Unless there is a good reason not to, it is recommended that you have the flu vaccine every year plus the vaccine against strains of pneumonia and the COVID vaccine as per standard schedule. Your GP practice can arrange these for you.

You should ideally avoid 'live' vaccines when you are taking thiopurines and for at least three months after stopping (vaccinations are always marked as live or inactive). If you are considering vaccinations (for example, for travel) check with your specialist team first.



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**How do I take the medication?** 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. Mercaptopurine is routinely available as a 50mg tablet.

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.

**How long will I be taking thiopurines?** The length of treatment depends on each person but it is likely to be for several years and longer in some cases.

**Do thiopurines interfere with other medicines?** Thiopurines can interact with other medicines. Please let your healthcare team know about all of the medicines that you are taking, including any over-the-counter or alternative medicines that you buy yourself. When you have started treatment, you should always check with your doctor or pharmacist before starting any new medicines.

Allopurinol, a medicine used for the treatment of gout, interacts with thiopurines 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 thiopurines. Other medicines which commonly interact with thiopurines include co-trimoxazole, trimethoprim and warfarin.

**Can I drink alcohol while taking thiopurines?** It is recommended that you keep well within the national recommended limits of alcohol consumption (maximum of 14 units per week). Any amount of alcohol can damage the liver, especially if you have an underlying condition such as autoimmune hepatitis. Depending on the

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condition of your liver, your specialist team may ask you to avoid alcohol completely.

**What should I do if I forget to take the thiopurine?** 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.

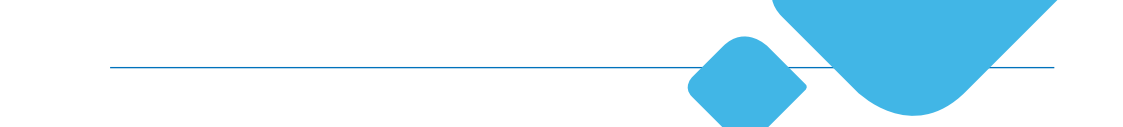
Thiopurines work slowly and therefore if you regularly forget the medication this will result in you having a lower level in your blood, potentially making it less effective.

**Are thiopurines safe in pregnancy & breastfeeding?** The most important thing is that your AIH is as controlled as well as possible during pregnancy and breastfeeding. It is important that you tell us if you are pregnant, planning on getting pregnant or breastfeeding so that we can review all of your medicines and monitor you more closely. Many patients continue to take thiopurines safely throughout their pregnancy and breastfeeding and your specialist team will be able to discuss the risks and benefits of continuing thiopurines during these times.

**Are there any side effects to thiopurines?** Thiopurines are generally very well tolerated. These medicines work by slowing down or moderating your body's over-active immune system and therefore you may be more likely to get an infection or take longer to recover from infection.

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

- Nausea may develop at the beginning of treatment but often goes away within a few weeks. You may find taking the medication with or after food or taking at night time reduces this effect. If not we may need to make adjustments.



- Flu-like symptoms (including headache, muscle ache, general malaise) may develop at the beginning of treatment but they are not usually serious, and often go away within a few weeks.

- Dizziness may develop at the beginning of treatment but often goes away within a few weeks. Switching to taking the medication at night-time during this time may help.

- Headache.

- Diarrhoea.

- Hair loss (many cases resolve despite continued treatment).

- Rashes – please stop the medication and contact a healthcare professional as soon as possible if you develop any signs of a rash after starting thiopurines.

More serious potential side effects are:

- 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/antimicrobials).

- 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 please stop the medication and contact a healthcare professional immediately.

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- Thiopurines increase the skin's sensitivity to the sun and so increases the risk of sunburn and certain types of skin cancer. It is important to take precautions in the sun, such as wearing protective clothing, seeking shade 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 people not taking thiopurines but it remains very rare (one in 2500 people).

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 – 4pm. 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.

## **Blood test monitoring**

When you first start thiopurines, you will need regular blood tests every 2 weeks for the first 8 weeks then again after 4 weeks. Following this the frequency of blood testing will be reduced to 3 monthly. When you first start the medication your specialist team will be monitoring your bloods remotely to assess for side effects or abnormalities on your blood tests and will contact you if there are any issues.

**How do I get a repeat prescription?** Your initial prescription will be issued by the hospital for the first two months. Once you are established on a stable dose, and if your GP agrees, prescribing will be handed over to your GP with advice from the specialist team. If any dose changes are needed, then the hospital will tell your GP.

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**Monitoring blood tests are essential. If these are not done your prescription may be withheld until up-to-date blood tests are obtained.**

**If you have any questions or concerns, please contact the Liver Specialist Nurses:**

Email [ruh-tr.hepatology@nhs.net](mailto:ruh-tr.hepatology@nhs.net)

Telephone 01225 826471

Monday & Friday 9.00-16.30

Tuesday, Wednesday, Thursday 9.00-12.30

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If you would like this leaflet in email form, large print, braille or another language, please contact the Patient Support and Complaints team on 01225 825656.

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