



**University
Hospitals Sussex**
NHS Foundation Trust

Thiopurines in Autoimmune Hepatitis

Patient information

Autoimmune Hepatitis, also known as 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.

Azathioprine & mercaptopurine are part of a group of medications called thiopurines which help to treat this condition. You will only need to take azathioprine or mercaptopurine – not both.

What are thiopurines?

Thiopurines are used to treat a variety of medical conditions including AIH. They slow down or moderate 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, TPMT (to measure the amount of enzyme you have in your blood that breaks down thiopurines), 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 contra-indicated, it is strongly recommended that you have the flu vaccine every year plus the vaccine against strains of pneumonia and the Covid vaccine as per standard schedule while on the medication. Your GP practice can arrange these for you.

How do I take thiopurines?

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 but taking it before going to bed can help if you are having problems with nausea (feeling sick) or dizziness. 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. It is important that all medications are kept out of the reach of children.

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 anything prescribed for you and any over-the-counter or alternative (herbal, homeopathic) medicines that you buy yourself, before you start treatment with thiopurines. 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 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, if you are experiencing lots of side effects or abnormal blood tests.

Other medicines which commonly interact with thiopurines include co-trimoxazole, trimethoprim and warfarin.

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

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 state 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.

It is important that you try not to forget any doses. 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.

Thiopurines 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 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.

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 nighttime reduces this effect. If not we may need to make adjustments to support you.
- 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 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/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.
- Thiopurines increases 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 regular 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 or have any concerns of the above 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.

Monitoring required while on thiopurines

When you first start thiopurines, you will need regular blood tests every 2 weeks.

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. In addition, you will have regular appointments or receive phone calls from them (approximately every 6 weeks) during the loading dose period.

We will also be monitoring the levels of thiopurine in your blood, and may adjust your dose depending on the results.

If your blood tests are stable after 3 months of treatment then you could continue to have them checked every 3 months with your GP who will continue the prescribing of the thiopurine.

Any dose changes or blood changes may require increased monitoring, but this will be advised by your specialist team.

How do I get a repeat prescription?

Your initial thiopurine prescriptions will be issued by the hospital during the loading dose period. Once completed your specialist team will advise your GP what dose to continue to prescribe. 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.

Where can I find more information?

More information of AIH and thiopurines can be found:

- **AIH Support:** <https://aihsupport.org.uk/about-aih/>
- **British Liver Trust:** <https://britishlivertrust.org.uk/information-and-support/living-with-a-liver-condition/liver-conditions/autoimmune-hepatitis/>

Contact us

If you have any questions or concerns about thiopurines, please contact the hepatology team via the secretaries on uhsussex.digestivediseasesmedsecs@nhs.net

For enquiries specifically about your liver medication, contact pharmacy team via email uhsussex.gastro.pharmacy.brighton@nhs.net

References:

Adapted from 'Azathioprine for autoimmune hepatitis' Patient Information Leaflet, Guys & St Thomas' NHS Foundation Trust. Ref number: 5077/VER1. October 2020. Available via <https://www.guysandstthomas.nhs.uk/resources/patient-information/gi/azathioprine-for-autoimmune-hepatitis.aspx>

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