

Azathioprine and mercaptopurine for inflammatory bowel disease: what you need to know

The leaflet answers some of your questions about taking azathioprine or mercaptopurine for inflammatory bowel disease (IBD). If you have any questions or concerns, please speak to a doctor, nurse or pharmacist caring for you.

What are azathioprine and mercaptopurine?

They are used to treat a variety of medical conditions including ulcerative colitis and Crohn's disease (both known as IBD). With IBD the body's defences are overactive and cause inflammation. Azathioprine and mercaptopurine suppress the body's immune system to treat the inflammation. They may also be used to prevent the formation of antibodies to other drugs, such as adalimumab or infliximab, that may be offered as part of your treatment.

Some patients may tolerate one of these drugs better than the other, but they work in the same way. Both drugs act slowly, so it may be up to 3 months before you feel any benefit.

In IBD we are using mercaptopurine outside of its licensed use. The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively you can call the pharmacy medicines helpline (contact details at the end of this leaflet).

What will happen before you start the medication?

You will need several blood tests to make sure it is safe for you to start the medication. These include TPMT (to measure the amount of enzyme you have in your blood that breaks down azathioprine and mercaptopurine), and tests for hepatitis B and C, HIV, Epstein-Barr virus and varicella (chicken-pox).

Before you start the medication it is strongly recommended that you have the vaccine against strains of pneumonia (pneumococcal). Your GP's practice can arrange this for you.

What dose should you take and how should you take it?

The dose depends on your weight. Typically doses vary from 25mg-200mg each day, and may be changed during the course of your treatment. Both drugs come as 25mg and 50mg tablets. For children, a liquid preparation of mercaptopurine is also available. You should take each dose with or immediately after food, to help reduce stomach upset.

People usually take the medicines in the morning, but taking them 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 sometimes we recommend splitting the dose throughout the day.

How long will you be taking it for?

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

Do azathioprine and mercaptopurine interfere with other medicines?

They can interact with other medicines. You should discuss with your doctor which medicines you are taking before starting the new drug. A drug used for the treatment of gout, called allopurinol, interacts with both drugs so they must not normally be taken together. However, in some cases this will deliberately be prescribed with a low dose of azathioprine or mercaptopurine for patients who are experiencing lots of side effects or abnormal blood tests.

Other medicines also interact, such as co-trimoxazole, trimethoprim and warfarin. Always check with your doctor or pharmacist before starting any new medicines. It is safe to drink alcohol in moderation.

You should avoid live vaccines when you are taking either of these medications. If you are considering vaccinations (for example, for travel) check with your doctor or pharmacist first.

What happens if you forget a dose?

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 to not forget any doses. Azathioprine and mercaptopurine work slowly and so if you regularly forget them it will result in you having a lower level in your blood, perhaps making it less effective.

Are azathioprine and mercaptopurine safe in pregnancy and breastfeeding?

The most important thing is that your IBD is as controlled as possible during pregnancy. There is no evidence to suggest that women taking this medicine when pregnant or breastfeeding would have a higher risk of harm to themselves or their baby. In most circumstances you would be advised to continue taking the medicine. It is important that you tell us if you are planning on getting pregnant, or find out that you are pregnant, so that we can review all of your medicines and monitor you more closely.

Are there any side effects?

These drugs work by suppressing the immune system so they may make you more prone to getting infections. Contact your GP if you begin to feel unwell and think you might have caught an infection.

These medications increase the skin's sensitivity to the sun, and so increase the risk of certain types of skin cancer. It is important to take precautions in the sun, such as wearing a hat and using a high SPF sun cream.

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

- nausea, especially at the start of treatment (changes to how and when you take the medication may be needed)
- flu-like symptoms may also develop at the beginning of treatment, but these are not normally serious and can often subside after a few weeks of treatment
- headache
- diarrhoea
- dizziness
- hair loss
- rashes.

More serious side effects are listed below. These will need closer monitoring, or in some cases, stopping the medication.

- The medications 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.
- Abnormal liver function tests can occur in about one in 20 (5%) patients. These will be monitored on your blood tests but if you notice jaundice (yellowing of the eyes or skin) then please tell us **immediately**.
- Pancreatitis occurs in about one in 30 people. It is inflammation of the pancreas and normally causes severe upper abdominal pain. If this happens, please contact us **immediately**.
- Lymphoma is a type of cancer affecting the lymph glands. The risk of getting this is higher than the general population but it remains very rare (one in 2,500 people).

Please tell the IBD Advice line as soon as possible if you experience any of the above side effects. Our contact details are at the end of this leaflet.

Is there anything else you should know?

- When you first start azathioprine or mercaptopurine you will need regular blood tests. Your full blood count (FBC) and liver function tests (LFTs) need to be checked 2, 4, 8 and 12 weeks after starting them.
- If your blood tests are stable after 3 months of treatment, you can continue to have them checked every 3 months with your GP.
- When you start the medication our specialist IBD pharmacists will monitor you to assess for side effects or abnormalities in your blood tests. Please expect to receive phone calls from them.
- We will also be monitoring the amount of active azathioprine in your blood, using a blood test called thioguanine nucleotides levels (TGNs). This may result in a change in your dose or the timing of your medication.
- It is important that all medications are kept out of the reach of children.
- It is recommended that you have the flu vaccine every year while on the medication.

How do you get a repeat prescription?

- After your hospital specialist has started azathioprine or mercaptopurine they will tell your GP what dose to prescribe. Usually your first prescriptions will be issued by the hospital until your GP has agreed to take over prescribing.
- If any changes to the dose are needed, 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

Crohn's and Colitis UK, for more information about IBD, **w:** www.crohnsandcolitis.org.uk

Contact us

If you have any questions or concerns about azathioprine or mercaptopurine, please contact the IBD pharmacists using **e:** gastropharmacist@gstt.nhs.uk or the IBD Advice line, **e:** ibdhelpline@gstt.nhs.uk. Messages will be responded to Monday to Friday, 9am-5pm. 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

This service 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

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Leaflet number: 4279/VER2

Date published: October 2020

Review date: October 2023

© 2020 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request