

Rheumatology Advice Line: 0207 288 5257

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Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or

whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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Disease Modifying Anti-Rheumatic Drugs (DMARDs)

Information for Patients

Rheumatology Service



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Frequently Asked Questions

Can I go abroad?

- Yes, however you must follow guidelines for sunscreen, monitor your alcohol intake, and seek urgent medical attention if you become unwell.
- You will need to advise your travel insurance of your diagnosis and any medications you are taking

What if I need surgery?

- It depends on the type of surgery you are having. Please contact the advice line for information.

COVID Vaccination

Your rheumatology team will advise you regarding COVID vaccination based on the latest Joint Committee on Vaccination and Immunisation (JCVI)/ government advice. We strongly recommend having the COVID vaccine and boosters when they are offered.

Over the counter medication

Always check with a Pharmacist if you can take over the counter medication to ensure it will not interact with your DMARDs.

NSAIDs (Non-Steroidal Anti Inflammatory Drugs, such as ibuprofen and naproxen) can be taken with methotrexate if clinically necessary and when there is no history of kidney disease.

It is recommended that you take anti inflammatory medications for as short a time as necessary given the potential for side effects with long term treatment. Please discuss with your GP or specialist nurse.

Why do I need these drugs?

You have been diagnosed with a type of Inflammatory Arthritis.

Inflammatory Arthritis is an autoimmune disease.

This happens when your immune system reacts abnormally and attacks your own tissues and joints causing inflammation.

There is no cure but we aim to control your disease get you into remission by using medication.

Disease Modifying Anti-Rheumatic Drugs (DMARDs)

These are the medications we use to treat inflammatory arthritis.

These work by modulating the immune system and stopping it attacking your joints.

The main ones used in Rheumatology are Methotrexate (MTX), Sulfasalazine (SSZ), Azathioprine (AZA), Leflunomide (LEFL) and Hydroxychloroquine (HCQ).

Taking these medications can make you more susceptible to infection. Avoid people visiting you if they are unwell.

Potential side effects

All medications have **potential** side effects. The main ones are headache, nausea, diarrhoea and vomiting and occasionally hair loss. These will usually pass if you can tolerate them however if side effects become unbearable then you must contact the advice line.

Some may also cause rashes and mouth ulcers however these are rare. If they do occur **STOP** taking the medication and contact the advice line.

There is a very rare risk of developing inflammation of the lungs called pneumonitis when taking MTX, SSZ and LEFL, if you develop a dry, tickly, persistent cough which lasts longer than three weeks and is not associated with a cold, hay fever or chest infection please contact the advice line.

Methotrexate (MTX)

This can be taken in tablet form or by subcutaneous injection and is taken once a week only. You will need to take a folic acid tablet usually once a week but NOT on the same day as MTX to reduce the risk of side effects. Please refer to your pack for details of the dosage. Please ensure that you are only ever given 2.5mg tablets of methotrexate and always check the strength every time you get a new prescription. The total weekly dose will be between 7.5mg to 20mg.

Better to take Methotrexate after your evening meal.

Methotrexate can take between 3 and 12 weeks to start working.

Sulfasalazine (SSZ)

Come in 500mg tablets these are started slowly, usually one tablet a day for a week and gradually increased to a target dose which is right for you. This must be taken after food.

Please see dosage instructions in your individual packs.

This medication will make your urine a dark orange colour and can stain your tears, this is nothing to be concerned about. If you wear contact lenses please let your nurse know.

If you develop a rash, you must STOP taking the sulfasalazine immediately and call the advice line.

Sulfasalazine can take 12-16 weeks to start working.

Leflunomide

Effective contraception should be used by both men and women and should continue for 2 years after stopping treatment.

If impractical to wait a wash-out can be recommended.

Please speak to the rheumatology team if you wish to conceive.

Sulfasalazine

Is safe to continue in pregnancy but to be combined with folic acid 5mg daily - please inform the rheumatology team. Taking SSZ can reduce the sperm count in men but is reversible within 2-3 months of stopping the medication.

Hydroxychloroquine

Generally thought to be safe in pregnancy and breast feeding.

Immunisation advice

Methotrexate and Leflunomide and Azathioprine

It is recommended that patients with auto-immune conditions taking immunosuppression should be offered the yearly flu vaccine and should also be offered a pneumococcal vaccination every 5-10 years depending on when the first dose is given.

If you are taking MTX/LEFL (and for six months after stopping) you must not have any Live vaccines so please check with the practice nurse before travelling to countries where vaccination is required.

Hydroxychloroquine and Sulfasalazine

Flu and pneumonia vaccine not required.

- Please do your blood test 1-2 days prior to picking up your next prescription as it cannot be dispensed without satisfactory blood tests and the results do not come back the same day.

Once you have been on a stable dose of Sulfasalazine for 1 year you no longer need a blood test unless you become unwell or commence any new medication which may affect your liver or blood count. Your doctor will be aware of these.

Can I drink alcohol?

When taking medication that can affect the liver it is important to monitor your alcohol intake.

The latest guidelines for alcohol state that we should not have more than 14 units per week and spread this out over the week and not to drink 14 units all in one go. It is also recommended that you should have two alcohol free days per week to avoid liver damage.

The liver damage that is caused by medication and alcohol can be irreversible (cirrhosis) and does not always show up in a blood test.

Pregnancy and fertility

Methotrexate

Adequate contraception **must** be used by women and continued for three months after stopping treatment with MTX. Breast feeding is also **not** recommended for women taking MTX.

Paternal exposure:

Based on evidence, MTX is compatible with paternal exposure.

Please speak to the rheumatology team if you wish to conceive.

Azathioprine (AZA)

This is taken in tablet form daily. They should be swallowed whole and taken with or after food.

You will usually start at a lower dose of 50mg and your doctor may increase this if necessary. Before prescribing AZA your team will do a blood test for an enzyme called TPMT.

TPMT helps to break down and remove azathioprine from the body. Low levels of TPMT may mean there is a slightly increased risk of side effects from azathioprine, so your doctor may suggest a lower dose.

If the TPMT result is very low, azathioprine may not be the right medication for you, and your team will discuss other treatment options.

AZA can take 6-12 weeks to start working.

Leflunomide (LEFL)

These tablets come in three different strengths 10mg, 15mg and 20mg. This is usually taken daily.

Please see dosage instructions in your individual packs.

Do not take if you have a peanut or soya allergy.

If you develop tingling/pins and needles of your hands or feet you must STOP taking LEFL and contact us as soon as possible.

If you develop a skin/mucosal reaction to LEFL you must STOP taking LEFL and contact us as soon as possible.

If you develop a skin/ mucosal reaction you may need to be treated with a washout – this is a medication taken orally for 11 days to washout the drug from your system.

Leflunomide can take six weeks before you notice it working but continues to work on dampening down the disease process for 6 months.

Hydroxychloroquine (HCQ)

This medication is prescribed in 200mg tablets daily and dependent on weight. Better to be taken **after food**.

There is no required blood monitoring for this medication.

You must however see an optician at the start of treatment and advise them you are taking this medication. You will need to have a yearly eye test to include retinal screen (check-up of the back of the eye).

Very rarely taking HCQ for a long period of time can cause loss of vision due to retinal toxicity; any gradual changes in vision see your optician. Any sudden onsets of blurred vision seek **urgent medical attention**.

Your skin will also become sun sensitive, and you **MUST** use a high factor sunscreen – and avoid sunbeds. If you develop a rash **STOP** immediately and contact the Advice Line.

Hydroxychloroquine can take between 12-16 weeks to start working.

What if I am unwell?

If you develop an infection, you must stop taking Methotrexate, Leflunomide, Azathioprine and Sulfasalazine until you are better and free from infection. These can usually be restarted one week after stopping antibiotics.

You can however continue to take Hydroxychloroquine.

If you are unsure whether or not to continue on your medication because you feel unwell then do not take it and contact the advice line.

If you take Methotrexate, you must not take certain medications, namely Trimethoprim/Septrin, an anti-epilepsy drug called phenytoin or anti-asthma medication called Theophylline. (These can increase the levels of methotrexate in your blood).

Blood monitoring

For Methotrexate, Leflunomide, Azathioprine and Sulfasalazine you will need to have regular blood tests as there is a very slight risk that taking these medications may suppress the bone marrow or raise the liver enzymes.

Please assume your blood test is satisfactory unless we contact you to tell you differently.

You will be required to have baseline blood tests if not already done so. Then:

- Once every 2 weeks for 6 weeks.
- Then once every 4 weeks x3 if blood tests are stable and there is no dose increase.
- Then once every 12 weeks if blood tests remain stable and there is no dose increase.
- Blood tests must occur at the hospital and prescriptions must be picked up from the hospital pharmacy
- Once you are stable on your DMARD your GP may be able to take over the prescription, please enquire with your team if you would be suitable for this