

# **Information for patients and carers**

## **Tablet Medication Options for Kidney Disease caused by the Immune System**



The immune system is the body's defense mechanism against infection. In certain illnesses this mechanism becomes inappropriately activated to target parts of the body. This type of illness is called an auto-immune disease. Medications such as **steroids, azathioprine, mycophenolate, methotrexate, ciclosporin, tacrolimus, voclosporin and avacopan** will lower the activity of the immune system to help treat disease. You may be treated with one or more of these medications. Your doctor will explain to you which one may be used as part of your treatment plan. Further information on each medication is listed below.

## What are the potential side effects of steroids?

Steroids, such as prednisolone, are a highly effective treatment in managing autoimmune conditions. In conditions such as vasculitis, they remain a crucial part of treatment in helping to get disease under control and reducing the risk of organ damage while other treatments take effect. Steroids have the potential for a wide range of side effects, which are listed below. The likelihood of experiencing these side effects often depends on the dose of steroids being used and how long they are taken for. Our team aim to try and reduce the risk of any potential side effects by using low doses and minimising how long steroids are taken for. In vasculitis, a low daily dose of steroid is generally reached by 10 weeks and may need to be continued for a total course of up to 12 months. Similar reduced dosing regimens are used in other conditions such as systemic lupus erythematosus, in line with recent trial data.

### Common potential side effects of steroids include:

- Increased risk of infection
- Reduced bone strength and increased risk of fractures
- Development of diabetes – this typically occurs in people who are already more likely to develop diabetes. It often improves when steroids are reduced or stopped
- Irritation to the lining of the stomach and stomach ulcers
- Weight gain
- Sleep/mood disturbance
- Easy bruising & stretch marks
- Slower healing of any wounds

- Muscle weakness
- Increased risk of glaucoma and cataracts

Additional medications will be prescribed to help reduce the risk of stomach irritation / ulcers and protect bone strength

## What are the potential side effects that can occur with azathioprine, mycophenolate, methotrexate, ciclosporin, tacrolimus or voclosporin?

**Infection:** As all these medications work by lowering your immune system, this will place you at increased risk of infection. You will have regular blood tests to help monitor your immune system.

**Cancer:** As well as fighting infection, another job of the immune system is to detect and get rid of any potential cancerous cells in the body. With any treatment that lowers the activity of the immune system, the potential risk of cancer in the future will go up. Following treatment with any of these medications, there is a very small risk of developing cancer in the future. To help reduce this risk, we strongly recommend you participate in any national screening programmes offered to you for breast, cervical, prostate and bowel cancer. We also recommend avoiding sunbathing and using high factor sunblock when you go out in the sun to reduce the likelihood of skin cancers.

**Feeling sick:** **Azathioprine, mycophenolate and methotrexate** may cause you to feel sick. Please tell your doctor if this occurs. After excluding other potential causes, your dose may be reduced, and you may benefit from anti-sickness medication. Alternatively, you may be changed to a different medication.

**Liver function:** Both **azathioprine** and **methotrexate** can affect your liver function. However, this is not common and if this does occur any changes are usually temporary and resolve after stopping the medication. Your liver function will be monitored as part of your routine blood tests.

**Diarrhoea & stomach discomfort:** These symptoms can occur with **mycophenolate**. Please tell your doctor if this occurs. After excluding other potential causes, your dose may need to be reduced or you may need to change to a different medication.

## What are the potential side effects that can occur with avacopan?

Compared to other medications that lower the activity of the immune system, avacopan is very targeted, only acting on a specific pathway of the immune system. This reduces inflammation by blocking recruitment of other cells of the immune system to the site of disease. Avacopan also has a unique targeted action to reduce disease activity in ANCA-associated vasculitis. As well as improved disease control, in select cases with less severe disease avacopan can also facilitate significantly reduced steroid use. Due to cost, the current use of avacopan is limited to patients who meet certain eligibility criteria.

Avacopan is normally well tolerated. Side effects are not commonly seen, but can include the following:

**Infection:** As avacopan affects the immune system, there is a small increased risk of infection. You will have regular blood tests to help monitor your immune system.

**Diarrhoea, feeling sick & stomach discomfort:** Although not common, these symptoms are listed as potential side effects of avacopan. Please tell your doctor if this occurs. After excluding other potential causes, your dose of avacopan may need to be reduced or withdrawn.

**Liver function:** Although can affect liver function. However, this is not common and if this does occur any changes are usually temporary and resolve after stopping the medication. Your liver function will be monitored as part of your routine blood tests.

## Taking my medication & drug level monitoring

**Prednisolone:** This should be taken in the morning with, or soon after food to avoid any potential stomach irritation. Prednisolone can affect your body's ability to produce its own natural steroid. It is very important you do not stop/reduce treatment by yourself as you may experience withdrawal symptoms and become very unwell. If you develop an infection or become generally unwell, you should seek urgent medical review.

**A cut out steroid card is available at the end of this leaflet. It is important that you carry this with you at all times and show it to any medical professional treating you.**

**Mycophenolate & Azathioprine:** Mycophenolate may come as tablets or capsules and are taken twice a day. Azathioprine tablets may be taken either once a day or twice a day depending on your prescription. Both mycophenolate and azathioprine should be taken with, or soon after food to avoid any potential stomach irritation. This should be at the same time every day.

Mycophenolate and azathioprine drug level monitoring is not routinely needed.

**Methotrexate:** Methotrexate is only taken once a week and should be taken on the same day every week. It should be taken with, or soon after food to avoid any potential stomach irritation.

**Tacrolimus, Ciclosporin & Voclosporin:** Depending on the brand, tacrolimus is either taken once a day or twice a day. Ciclosporin also has several available brands, but is always taken twice a day. Voclosporin is taken twice a day. It is important that you stay on the same brand prescribed by your doctor. The dose should be taken on an empty stomach, either one hour before or two to three hours after eating. This should be at the same time every day.

Tacrolimus and ciclosporin both require monitoring to ensure the right therapeutic level.

For once daily preparations of tacrolimus, blood tests should be done 24 hours after your last dose. For example, if you take your dose at 09:00, you should have your blood test between 08:00-09:00 the following morning prior to taking the morning dose.

For twice daily preparations of tacrolimus and ciclosporin, a blood test should be done in the morning 12 hours after taking your evening dose. For example, if you take your evening dose at 21:00, you should have your blood test between 08:00-09:00 the following morning prior to taking the morning dose.

Voclosporin does not currently require routine drug monitoring.

**Avacopan:** Avacopan is available in 10mg capsules. The typical prescribed dose is 30mg twice a day. You should taken three capsules twice a day. This should be at the same time every day.

## What if I forget to take a dose?

**Prednisolone:** If you miss a dose, take it as soon as possible. However, if it is almost time for your next dose, skip the dose and go back to your regular dosing schedule. Do not double the dose.

**Mycophenolate & Azathioprine:** For twice daily dosing of mycophenolate and azathioprine, if you miss a dose and are within 6 hours of your usual time, take it as soon as you remember. If it is more than 6 hours from your usual dose, skip the dose you missed and take your next dose at the normal time. Never take two doses at any one time.

For once daily dosing of azathioprine, if you miss a dose and are within 12 hours of your usual time, take it as soon as you remember. If it is more

than 12 hours since your dose was due do not take the dose and take your next dose at the normal time. Never take two doses at any one time.

**Methotrexate:** If you miss a dose of your methotrexate, take it when you remember. For example, if your usual dose is taken on Monday, you can take it on Tuesday and this will become your new day of the week to take future doses. Never take two doses at any one time.

**Tacrolimus, Ciclosporin & Voclosporin:** If on a twice a day preparation of either tacrolimus, ciclosporin or voclosporin and you forget to take a dose but remember within 6 hours of your usual time, then take your dose as usual. If you remember after this time, do not take the missed dose and take your next dose at your normal time.

If on a once a day preparation of tacrolimus and you forget to take a dose but remember within 12 hours of your usual time, then take your dose as usual. If you remember after this time, do not take the missed dose and take your next dose at your normal time.

**Avacopan:** If you have missed a dose of avacopan, but have more than 3 hours until your next scheduled dose, take the missed dose as soon as possible and then take your next dose at your usual time. If it is less than 3 hours to your next usual dose, do not take the missed dose and continue with your usual dosing schedule. Never take two doses at any one time to make up for a forgotten dose.

## Other guidance

**Pregnancy & breast feeding:** Pregnancy and breast feeding are not recommended when taking mycophenolate, methotrexate, voclosporin or avacopan, and for the 3 months after stopping these medications. Contraception is advised for both men and women while taking these medications and for 3 months after stopping them. Azathioprine, ciclosporin, tacrolimus and steroids are all safe during pregnancy and breast feeding.

**Can I take other medications while taking any of the medications listed above?** Medications can interact with each other, changing how effective there are or potentially cause toxicity. Before starting a new medication, you should always tell the prescribing doctor if you are taking azathioprine, mycophenolate, methotrexate, tacrolimus, ciclosporin, voclosporin, avacopan or steroids. Please check with your doctor or pharmacist before taking any 'over-the-counter', herbal, or complementary medicines.

**Should I avoid any particular food or drinks when taking any of the above medications listed above?** Grapefruit can interact with mycophenolate, methotrexate, tacrolimus, ciclosporin, voclosporin and avacopan. It should be avoided when taking any of these medications.

**Can I have vaccinations while taking any of the medications listed above?** As azathioprine, mycophenolate, methotrexate, ciclosporin, tacrolimus, voclosporin, avacopan and steroids can all lower your immune system and ability to fight infection, they may also reduce the effectiveness of any administered vaccine. When considering live vaccines, this should be avoided while you are on treatment with azathioprine, mycophenolate, methotrexate and avacopan. Talk to your doctor before having any vaccinations while you are receiving treatment.

**Can I drink alcohol while taking any of the medications listed above?** Yes, in moderation and within current recommended safe limits.

## **What are the alternatives?**

Based on your individual needs and understanding of the disease, your team may have recommended a certain treatment option. Other medications may be considered depending on the disease being treated. There is also the option not to undertake any treatment. The lack of any treatment would carry a significant risk of uncontrolled disease and organ damage. In diseases that can affect multiple organs, such as vasculitis or lupus, there is the potential for death without any treatment.



## Contact details

Should you require further advice or information please contact the Renal department on telephone: **01772 522739**.

## Sources of further information

[www.lancsteachinghospitals.nhs.uk](http://www.lancsteachinghospitals.nhs.uk)  
[www.nhs.uk](http://www.nhs.uk)  
[www.accessable.co.uk](http://www.accessable.co.uk)  
[www.patient.co.uk](http://www.patient.co.uk)  
[www.lancsteachinghospitals.nhs.uk/veteran-aware](http://www.lancsteachinghospitals.nhs.uk/veteran-aware)  
<https://bepartofresearch.nihr.ac.uk/>

If you would like any further information or have any questions about your planned treatment, please speak with your consultant and treating team.

More information about vasculitis can be found on the Vasculitis UK and Versus Arthritis websites which are listed below.

The Northwest Vasculitis Support Group is made up of patients in the Lancashire region. They are a great source of patient support, also welcome family, friends and carers.

**Vasculitis UK** - [www.vasculitis.org.uk](http://www.vasculitis.org.uk)

**Versus Arthritis** - [www.versusarthritis.org](http://www.versusarthritis.org)

**Northwest Vasculitis Support Group** - [nwvasculitis@outlook.com](mailto:nwvasculitis@outlook.com)

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All our patient information leaflets are available on our website for patients to access and download:

[www.lancsteachinghospitals.nhs.uk/patient-information-leaflets](http://www.lancsteachinghospitals.nhs.uk/patient-information-leaflets)

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If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638**.

**Please ask a member of staff if you would like help in understanding this information.**  
**This information can be made available in large print, audio, Braille and in other languages.**

Our patient information group review our leaflets regularly, if you feel you would like to feedback on this information or join our reading group please contact on email address:

[patientexperienceandinvolve@LTHTR.nhs.uk](mailto:patientexperienceandinvolve@LTHTR.nhs.uk)

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## **STEROID TREATMENT CARD**



**I am a patient on STEROID treatment which must not be stopped suddenly**

- If you have been taking steroids (e.g. prednisolone) for more than three weeks the dose should be reduced gradually when you stop taking it unless our doctor says otherwise
- Always carry this card with you and show it to anyone who treats you (for example a doctor, nurse, pharmacist or dentist). For one year after stopping treatment, you must mention that you have previously taken steroids.
- If you become ill or come into contact with anyone who has an infectious disease consult your doctor promptly.