

Tacrolimus for the treatment of autoimmune hepatitis (AIH)

Information for patients

This leaflet contains information about tacrolimus, which is a medication that can be used to treat autoimmune hepatitis (AIH), a condition in which your body's immune system attacks your liver. If you have any other questions or concerns, please do not hesitate to speak to the doctors or nurses caring for you.

What is tacrolimus?

Tacrolimus is a medicine used to suppress the immune system to prevent inflammation of the liver. Tacrolimus helps to prevent flare-ups and helps to control or reduce symptoms. The dose will be adjusted depending on the medication levels in your blood.

Tacrolimus preparations

There are different brands of tacrolimus and it is very important that you remain on the same brand that your hospital specialist starts you on.

You must not switch between different brands unless your hospital specialist tells you to do so.

Certain brands are taken once per day, others are taken twice per day. It is very important that you know which preparation you are on and that you do not inadvertently switch between brands. When you collect your prescription from your pharmacy, check you have received the correct brand.

1. Immediate-release tacrolimus (for example, Prograf®, Adoport®).

This preparation is taken twice per day, about 12 hours apart. Choose times suitable to you for example, 8am and 8pm or 10am and 10pm. Swallow the capsules whole with a glass of water, 1 hour before or 2 hours after food.

What to do if you forget to take a dose:

If you remember within 6 hours of when you usually take the dose, then take it when you remember and take your next dose at the usual time. If you remember over 6 hours from when you usually take the dose, forget this dose and take your next dose at the usual time.

Never take a double dose to make up for missed doses.

2. Prolonged-released tacrolimus (for example, Advagraf®, Envarsus®).

This preparation is taken once per day, in the morning. Swallow the capsules whole with a glass of water, 1 hour before or 2 hours after food.

What to do if you forget to take a dose:

If you remember within 12 hours of when you usually take the dose, then take it when you remember and take your next dose at the usual time. If you remember over 12 hours from when you usually take the dose, forget this dose and take your next dose at the usual time.

Never take a double dose to make up for missed doses.

Dose

The dose will be altered according to how much of the medicine is in your blood. This is checked by a blood test at the clinic.

If your blood tests show that you need to have your dose changed (up or down), you will be contacted.

All types of tacrolimus preparation come in capsule form and are available as different strengths.

You will be provided with different strengths of tacrolimus to enable you to make up your dose, for example, 1 mg and 0.5 mg capsules.

Should I take tacrolimus on the day that I have a clinic appointment?

The level of tacrolimus in your blood is checked when it is at its lowest. This will be just before you are due to take a dose, so do not take tacrolimus before you are due to have a blood test.

On the day that you attend your clinic you should not take your morning dose but bring it with you to take after you have had your blood test. This allows the medicine concentration to be accurately measured.

Side effects of tacrolimus

Tacrolimus has several side-effects but not everyone will experience them. Some of the side-effects disappear as the dose of tacrolimus is reduced over time.

Listed below are the most common side-effects:

- tremor (shaking) of the hands
- headache
- vivid dreams
- upset stomach
- hair loss on head
- numb, hot or tingly hands, feet or mouth
- diabetes
- high blood pressure
- reduced kidney function
- increased risk of infections
- an increase in the risk of certain cancers

You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution.

Monitoring

As mentioned, you will have the tacrolimus level in your blood checked to ensure you are on the correct dose.

Your kidney function, liver function, full blood count and blood pressure also will be monitored while you are on tacrolimus.

Taking other medicines with tacrolimus

Some medicines can increase or decrease the tacrolimus level in your blood. Always check with your doctor or pharmacist if you are prescribed new medications or if you buy any new medicines over the counter, including herbal medicines.

There are various medicines that you should NOT take while on tacrolimus. Some examples include:

- antibiotics called erythromycin, clarithromycin
- non-steroidal anti-inflammatory medicines such as ibuprofen or diclofenac
- some antifungals called fluconazole

Always check with a doctor or pharmacist that any new medicine is safe for you to take. If you are in doubt, contact one of the hospital pharmacists.

Fruits to avoid with tacrolimus

You should avoid eating grapefruit or Seville orange or drinking grapefruit or Seville orange juice while you are taking tacrolimus because it contains a chemical that affects the level of tacrolimus in your blood.

Other citrus fruits are safe to eat or drink.

Storage

Most tacrolimus preparations come in an aluminium wrap. Once this has been opened, the capsules expire after 1 year. Store in the original package to protect from moisture.

Supply

You will receive your tacrolimus from hospital when you attend your out-patient appointments. As this is a specialist medicine, the supply cannot come from your local community pharmacy. You will be supplied with enough medication to last until your next clinic appointment. If for some reason, this does not align, you should e-mail the liver secretaries who can contact the prescriber who reviewed you in clinic and will be able to arrange a prescription. If this occurs, please ensure you contact the team at least two weeks before you are due to run out of your tacrolimus.

Taking tacrolimus if you are pregnant or breastfeeding

Talk to your doctor if you are pregnant, plan to get pregnant or think you are pregnant to ensure tacrolimus is still appropriate. Tacrolimus is one of the safer options in pregnancy. Please do not stop taking tacrolimus if you discover you are pregnant without discussing with the team. Tacrolimus can also be found in breast milk. If you are breastfeeding or planning to breastfeed, talk to your doctor or pharmacist before taking tacrolimus.

Vaccines

Some vaccines contain a live form of the virus. These are called live vaccines. If you are taking tacrolimus, you cannot have live vaccines. Please talk to your liver doctor or pharmacist if you are not sure about this.

It is still important to get the following:

Flu vaccine: recommended

COVID-19 vaccine: recommended

Pneumococcal vaccine (Pneumovax®): recommended

Shingles vaccine (Shingrix®): make sure that you get the NON-LIVE formulation

Is it safe to be in the sun?

Tacrolimus can increase risk of sunburning, and so national advice on sun safety should be followed:

- limit the amount of time you spend in the sunlight and seek shade from 11am to 3pm
- never burn, wear protective clothing and sunglasses
- use high sun protection factor (at least SPF 30)
- regularly check your skin for changes (for example, new moles or mole changes)
- avoid exposure to additional ultraviolet (UV) light, such as tanning machines

Additional information

If you take tacrolimus, you may be more at risk of getting infection.

If you come into skin contact with someone with chickenpox or shingles, or if you develop chickenpox or shingles, you need to contact your doctor immediately.

How can I find out more?

If you would like any more information on tacrolimus, or if you need to get in contact with a member of the liver team, please contact the team using the details below (available Monday to Friday, from 9am to 5.30pm).

Liver Outpatients: kch-tr.liver.outpatients@nhs.net

Liver Pharmacy Team: kch-tr.liverpharmacy@nhs.net

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND

Tel: 01689 863252

Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net