



**University
Hospitals Sussex**
NHS Foundation Trust

Tacrolimus in autoimmune hepatitis

Pharmacy

Patient information

What is this information about?

This information is about a medicine called tacrolimus. It is used to treat Autoimmune Hepatitis, also known as AIH. 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.

This information tells you about how and when to take tacrolimus; what happens before you take tacrolimus; things that should be aware of while you are taking it; possible risks and side-effects. It also tells you how the specialist liver team will look after you while you take it, and how to contact them should you need to.

What is tacrolimus?

Tacrolimus is a medication that is used to treat different medical conditions including AIH.

Tacrolimus works by slowing down or moderating your body's over-active immune system.

How long does it take to work?

Tacrolimus can take 6-12 weeks before the full effect is seen.

What are the different names for tacrolimus?

Tacrolimus has different brand names.

Be advised

It is important you always take the same brand of tacrolimus. Get to know your brand and do not accept a different brand unless told to by your specialist team.

Brands	Strengths available	How taken
Prograf®	0.5mg, 1mg, 5mg	Immediate release so is taken twice a day, 12 hours apart.
Advagraf®	0.5mg, 1mg, 3mg, 5mg	modified release so is taken once a day.
Envarsus®	0.75mg, 1mg, 4mg	modified release so is taken once a day.

Stopping tacrolimus will increase the chance of an autoimmune flare. Do not stop taking tacrolimus unless your doctor/specialist team tells you to. If you are concerned about side effects, please contact your specialist team (details below).

What will happen before I start tacrolimus?

You will need to let your specialist team know if you have an allergy to macrolide antibiotics for example, azithromycin, clarithromycin or erythromycin.

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 and tests for viral infections, including:
 - Cytomegalovirus (CMV).
 - Epstein-Barr virus (EBV).
 - Hepatitis B and C.
 - HIV.
 - Varicella (chickenpox and related viral infections).

Recommended vaccinations while on tacrolimus

Unless there is a medical reason that you cannot have them, we recommend that you have the following:

- The flu vaccine (every year).
- The vaccine against strains of pneumonia.
- The Covid vaccine (as per current national schedule).

If you are over 50 years old and have had prednisolone at 10mg or more a day for more than four weeks in the past three months, we recommend the non-live shingles (Shingrix) vaccine programme. Your GP practice can arrange this for you.

If you need vaccinations for travel, check with your specialist liver team first. You should not have live vaccines while on tacrolimus, and for three months after stopping it. If you have been recommended to have a live vaccine or not sure if a vaccine is live, please contact the specialist team (details below).

How do I take tacrolimus?

- Do not take the tablet or capsule out of the foil strip until you are ready to take it.
- Take on an empty stomach, at least one hour before or two hours after food. If you have to take it after food you must avoid fatty food as this affects the absorption of tacrolimus into the body.
- Swallow the capsules whole with water.
- It is important you take your tacrolimus regularly and approximately the same time(s) each day.
 - Prograf® is usually taken twice a day, 12 hours apart.
 - Advagraf® and Envarsus® are taken once daily, usually in the morning.

- You must never take more than one brand of tacrolimus at any one time.
- While taking tacrolimus, do not (at any time):
 - Drink grapefruit juice.
 - Take St John's Wort (*hypericum perforatum*).
 - Eat pomelos or Seville oranges (usually found in Seville marmalade).

How long will I be taking tacrolimus?

The length of treatment depends on each person. It is likely to be for several years and longer. Some people take it all their lives.

Can I stop taking tacrolimus at any time?

No. Stopping tacrolimus will increase the chance of an autoimmune flare. Do not stop taking tacrolimus unless your specialist team tells you to.

If you are concerned about side effects, please contact your specialist team (details below).

Does tacrolimus interfere with other medicines?

Tacrolimus can interfere with other medicines. Please let your healthcare teams know about all of the medicines that you are taking, including:

- Anything prescribed for you.
- Any medicines you bought from a pharmacy or shop.
- Alternative (herbal, homeopathic) medicines that you buy yourself.

before you start treatment with tacrolimus.

When you have started treatment, you should always check with your doctor or pharmacist before starting any new medicines.

If you have had an allergy to macrolide antibiotics, for example, azithromycin, clarithromycin or erythromycin, please let your specialist team know.

Can I drink alcohol while taking tacrolimus?

Any amount of alcohol can damage the liver, especially if you have an underlying condition such as AIH.

Your specialist team may ask you to avoid alcohol completely.

If you are allowed to drink alcohol, it is recommended that you keep well within the national recommended limits of alcohol consumption. This is a maximum of 14 units per week. Please see **Alcoholic drinks and units | Drinkaware** <https://www.drinkaware.co.uk/facts/information-about-alcohol/alcoholic-drinks-and-units/> for more information.

What if I forget to take a dose?

This depends on which brand of tacrolimus you take:

- **Prograf®**: As this is taken twice per day, you have 6 hours to take the medication. If you realise you have missed it after this time, wait and take the next dose as usual. Do not take a double dose to catch up.
- **Advagraf® and Envarsus®**: As this is taken once daily, a forgotten dose should be taken as soon as possible on the same day. A double dose should not be taken on the next day.

It is very important you take your tacrolimus regularly and approximately the same time(s) each day. Frequently missing doses increases your chance of causing a flare-up of your autoimmune condition.

What if I take too many?

Get help immediately:

- From your specialist team, Monday to Friday, 9am to 4pm. Contact details are below.
- Outside of these hours, please contact **NHS 111**, an out of hours GP, or attend an emergency department (A&E) if you are very unwell.

Is tacrolimus safe in pregnancy and 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 your specialist team if you are pregnant, planning on getting pregnant or breastfeeding so that we can review all of your medicines and monitor you more closely.

Are there any side effects to tacrolimus?

Contact a healthcare professional if you experience or have any concerns about any of these side effects.

You can contact your specialist team during regular working hours Monday to Friday 9am to 4pm (see below for contact details).

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.

Infection

Tacrolimus works by slowing down or moderating your body's over-active immune system. 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. This includes signs of fever, a sore throat or cough.

Listed common side effects:

- Hair loss.
- Your blood counts may be affected.
- Stomach upset or loss of appetite.
- Headaches.
- Tremors.
- Acne or skin reaction.
- Can affect kidney function tests.
- Raised blood pressure.
- Increased blood sugars.
- Sleep disturbance.
- Numbness or tingling in the hands or feet.
- Tinnitus.
- Weight changes.
- An increase in the risk of certain cancers.

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

- Seek shade from 11am to 3pm
- Never burn, cover with suitable clothing and sunglasses

- Use high sun protection factor (at least 30)
- Regularly check your skin for changes (for example, new moles or mole changes).

If you have any eye concerns, please see your GP, or if out of hours call **111** for prompt review.

It may affect skilled tasks (for example, driving) and you should not drive if you are affected.

What monitoring do I need while I am on tacrolimus?

Your dose of tacrolimus is based on the levels in your blood, your kidney and liver function and your general response to the medication. Taking too much may increase the chance of side effects, while taking too little may lead to flare of your auto-immune condition.

Lots of factors change how your body absorbs tacrolimus and this can change the level of medication in your body. This means we have to monitor the levels very closely.

We will monitor your blood tests to make sure that the tacrolimus is working correctly and not affecting your bloods. It is important you do your bloods when you are asked to. This will help to keep you safe.

Your specialist team will let you know what bloods are needed and when. At the beginning they are usually every two weeks for at least six weeks. Once they are stable, they could move to every three months.

To get the most accurate level of tacrolimus, the best time to have a blood test is just before your morning tacrolimus dose. Once the blood test is completed, please take your morning tacrolimus dose afterwards.

How do I get a repeat prescription?

At the start of taking tacrolimus, the hospital will supply it.

Once you are stable on the medication, the hospital may be able to arrange that you can get this medication from your GP. If this is not possible then the hospital will continue to supply it.

If you are running out between appointments, then please email the gastroenterology pharmacy team. Their contact details are below.

Where can I find more information?

More information about AIH can be found:

- AIH Support website <https://aihsupport.org.uk>
- British Liver Trust <https://britishlivertrust.org.uk/information-and-support/liver-conditions/autoimmune-hepatitis/>

How do I contact the specialist liver team or gastroenterology pharmacy team?

- If you have any questions or concerns about your AIH, please contact the specialist liver team at: uhsussex.digestivediseasesmedsecs@nhs.net
- If you have questions about your liver medication (including repeat prescriptions), contact the gastroenterology pharmacy team at: uhsussex.gastro.pharmacy.brighton@nhs.net

Ref. number: 2392
Publication date: 09/2024
Review date: 09/2027

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