

Patient information

Twice Daily Tacrolimus Drug Use in Connective Tissue Diseases in Secondary Care

Rheumatology Department

What Tacrolimus is and how it is used

Tacrolimus belongs to a group of medicines known as immunosuppressants and works by reducing the activity of your body's immune system.

Tacrolimus is used to treat a number of conditions which are caused by the body's reaction to its own tissue, including severe asthma, lung disease, rheumatoid arthritis, connective tissue disease (CTD) e.g systemic lupus erythematosus (SLE). It also is used widely in patients that have organ transplants to prevent the body rejecting the transplant. It works by slowing down how active your condition is, rather than just treating how its symptoms affect you.

When your immune system is working properly, it protects you by fighting off infections and illness. However, in inflammatory conditions, your immune system may attack parts of your body by mistake. For this reason, tacrolimus is recommended and used as a useful treatment of CTD, however, it is only officially licenced in the UK in organ transplant.

Why have I been given Tacrolimus?

CTD is caused by your immune system overacting or reacting abnormally which cause illness. Tacrolimus is used in some patients with CTD often in combination with other medications but also in some patients who have not responded to or have not tolerated other treatments. Your doctor may prescribe tacrolimus if you are on steroid treatment in order to try and reduce your steroid dose or stop it completely.

How long will it take to work?

Tacrolimus does not work immediately. It can take up to 12 weeks before you notice any benefit. Unless you have severe side effects it is important to continue taking it even if you do not notice any change in your symptoms.

What dose do I take?

The starting dose of tacrolimus is 0.5mg twice daily. Depending upon your weight and blood tests, the dose will be adjusted according to the levels of the drug measured in your blood when you attend for regular blood tests.

When and how to take tacrolimus

Tacrolimus is given as a capsule and should usually be taken twice a day (morning and evening). You should take tacrolimus at roughly the same time each day.

The capsules should be swallowed with a glass of water on an empty stomach (one hour before food, or three hours after food). Grapefruit or grapefruit juice should be avoided whilst taking tacrolimus.

Capsules should be taken immediately after being popped from foil so avoid dosette boxes.

You should always receive the same brand of tacrolimus because the amount of tacrolimus absorbed into the bloodstream may vary between brands made by different manufacturers.

If you have missed a dose, take it as soon as you remember. If it is nearly time for the next dose, do not take the one you missed. Take the next dose at the usual time. Do not double the dose.

If you think you have taken too much tacrolimus, call your Specialist Team or the NHS helpline 111.

Do I need any specialist checks whilst on Tacrolimus?

Blood tests will be required before commencing Tacrolimus to ensure it is safe for you to take. Weight and blood pressure will be assessed, and you may be required to have an ECG (heart tracing).

On commencing tacrolimus, tacrolimus blood levels (blood test) will be every two weeks until in therapeutic range continuing for two weekly for six weeks once in therapeutic range, then every four weeks for up to 12 months going to three monthly if consistently in range.

Occasionally checks of your magnesium and calcium level may be required especially if you are Omeprazole, Lansoprazole, Esomeprazole, Pantoprazole or Rabeprazole.

Blood pressure monitoring may also be required every four weeks, and/or repeat ECG if indicated once commenced on Tacrolimus. We encourage you to record home BP readings, as these will be more accurate. Your specialist nursing team will give you details of how to report these readings.

Possible risks and side effects

All medicines can cause unwanted side effects. The most common side effects include:

- Stomach upsets, such as feeling sick or diarrhoea.
- Headache, tremor or high blood pressure
- High blood sugar levels

- Tacrolimus can affect your kidneys and liver, so you will need to have regular blood tests to monitor the levels.
- Hair loss, rash.
- Visual disturbance
- You are more likely to catch infections so avoid close contact with people with severe active infections.
- Although it is rare, there is a slightly increased risk of certain types of cancers, such as skin cancer, in people taking tacrolimus. Skin cancers can often be treated successfully when diagnosed early. Make sure you use sunscreen and regularly check your skin for any new spots or changes to your freckles or moles.

While you are taking Tacrolimus, contact your Specialist Team straight away if you start experiencing any **new** symptoms or anything that concerns you. Let them know immediately if you have:

- A sore throat, fever, flu-like symptoms.
- New or worsening constant cough or shortness of breath
- Unexplained bruising or bleeding
- Yellowing of the skin or eyes (jaundice)
- The sensation that your heart is beating unusually.
- Night-time leg cramps
- Numbness or tingling in the legs or hands.
- Tremors.
- Heart palpitations

If you come into contact with someone with chicken pox or shingles, you should see your family doctor (GP) immediately and contact your Specialist Team.

Tips to reduce your risk of infection

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry round a small bottle of antibacterial gel to use.
- Keep your mouth clean by brushing your teeth regularly.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic especially the kitchen, bathroom and toilet.
- Stop smoking if you are a smoker.

Does tacrolimus interfere with other medications?

Tacrolimus can interact with other medications. Other medications which can cause problems with tacrolimus include:

- Some antifungal and antibiotic medications, e.g., fluconazole and clarithromycin
- Anti-epileptic medication, e.g., phenytoin and carbamazepine
- Some blood pressure medications e.g., diltiazem and verapamil
- You should only take non-steroidal anti-inflammatory drugs (NSAIDs) on the advice of your GP or doctor.
- St John's Wort and most other herbal preparations should be avoided.
- Always check with your doctor or pharmacist first before starting any new medication.

Alcohol

Tacrolimus and alcohol can both affect your liver, so you should only drink alcohol in small amounts, and it is recommended to have alcohol free days without saving units up to drink all in one go.

Vaccinations

Whilst taking Tacrolimus you should avoid live vaccines, such as yellow fever. However, in certain situations a live vaccine may be necessary, so speak to your Specialist Team about this for advice.

Flu, Covid and Pneumonia vaccines are non-live and safe to have. Shingles vaccine, routinely offered to people aged between 70-80 and available to some eligible patient's over 50, can be live or non-live. If offered the shingles vaccine, or any other vaccine not mentioned, please check if it is live or non-live and request the non-live version.

Does tacrolimus affect fertility and pregnancy?

If you are planning a family or become pregnant while taking tacrolimus, you should discuss this with your Specialist Team as soon as possible.

Current guidelines say that tacrolimus can be taken if you are trying for a baby and even when pregnant or breastfeeding. Men are also fine to continue taking it when trying for a baby.

Further information

Rheumatology Nurse Team: Monday – Friday

If your treatment is at Broadgreen Hospital (Rheumatology):-

Vasculitis Tel: 0151 282 6052 or 0151 706 3244

Lupus Tel: 0151 282 6047 or 0151 706 3244

Rheumatology Nurse Helpline Tel: 0151 282 6060

If your treatment is at Aintree Hospital (Rheumatology):-

Vasculitis/Behcet's Tel: 0151 529 8123

Rheumatology Nurse Helpline Tel: 0151 529 3034

Lupus Tel: 0151 282 6047 or 0151 706 3244

Author: Lupus Specialist Team, Rheumatology

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