



Tacrolimus for prevention of transplant rejection

This leaflet is about the use of tacrolimus to prevent rejection of a transplanted organ (kidney, heart, liver or other organ).



This leaflet has been written for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adult patients. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Do not stop giving tacrolimus, as your child's transplanted organ may be rejected and they may become seriously ill.

Do not change the brand or type of tacrolimus without talking to your doctor first, as there may be toxic effects or organ rejection.

Name of drug

Tacrolimus

Brand names: Prograf®, Adoport®, Modigraf®, Capexion®, Tacni®, Vivadex®

Modified-release: Advagraf®

Why is it important for my child to take this medicine?

Tacrolimus belongs to a group of medicines called immunosuppressants. These medicines help to stop the body's immune system from attacking a transplanted organ. It is vital that your child takes this medicine regularly to prevent the organ being rejected.

What is tacrolimus available as?

- **Capsules** (Adoport®, Prograf®, Capexion®, Tacni® and Vivadex®): 0.5 mg, 1 mg, 5 mg; these may contain small amounts of lactose
- **Modified-release capsules** (Advagraf®): 0.5 mg; 1 mg; 3 mg and 5 mg
- **Granules** (Modigraf®): 0.2 mg and 1 mg sachets
- **Liquid medicine:** you may be able to order liquid medicine from your pharmacist

When should I give tacrolimus?

For Adoport®, Prograf®, Capexion®, Tacni® and Vivadex® capsules, and Modigraf® granules

- Tacrolimus is usually given **twice each day**, once in the morning and once in the evening. Ideally, these times are 10–12 hours apart, for example some time between 7 and 8 am, and between 7 and 8 pm.

For modified-release Advagraf® capsules

- Modified-release capsules are given **once each day**. This is usually in the morning.

 It is particularly important to give this medicine at about the same time(s) each day. You can use an alarm clock or the reminder on your mobile phone to remind you.

How much should I give?

Your doctor will work out the amount of tacrolimus (the dose) that is right for *your* child. The dose will be shown on the medicine label.

 **It is important that you follow your doctor's instructions about how much to give.**

How should I give it?

This medicine is best taken when the stomach is empty. Give it at least 1 hour before a meal or at least 2 hours after a meal.



Adoport®, Prograf®, Capexion®, Tacni® and Vivadex® capsules: Remove the capsule from the package and give it to your child straight away. Capsules should be swallowed whole with a glass of water, squash or milk. Your child should not chew the capsule.

You can open these capsules and stir the contents into a glass of water, or mix with a small amount of soft food such as honey, jam or yogurt. Your child should swallow it all straight away. You must be careful not to inhale the powder in the capsule. Wash your hands thoroughly after handling the capsules, and anything else that the powder has been in contact with. This is to make sure that the medicine does not affect anyone else's immune system.



Advagraf® capsules should be swallowed whole with a drink of water, squash or milk. Your child should not chew these capsules. You should not open these capsules, as they will not work properly.



Modigraf® granules: Cut the sachet open with scissors. Tip the contents into a glass of water and stir until dissolved. Your child should drink it all straight away. You can give the mixture to your child using a spoon or oral syringe.



Liquid medicine: Measure out the right amount using a medicine spoon or oral syringe. You can get these from your pharmacist. Do not use a kitchen teaspoon as it will not give the right amount.

When should the medicine start working?

The medicine starts to work as soon as your child starts taking it. You will not see any difference in your child. However, they must continue to take it as your doctor has told you to, otherwise the transplanted organ will be rejected by the body.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of tacrolimus, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of tacrolimus, you **do not** need to give them another dose. Wait until the next normal dose.

If your child is sick again, seek advice from your GP, pharmacist or hospital. They will decide what to do based on your child's condition and the specific medicine involved.

What if I forget to give it?

If you usually give tacrolimus twice a day

If you remember up to 6 hours after you should have given a dose, give your child the missed dose. For example, if you usually give a dose at about 7 am, you can give the missed dose at any time up to 1 pm. If you remember after that time, **do not** give the missed dose. Wait until the next normal dose.

If you usually give tacrolimus once a day

Give the missed dose as soon as you remember, as long as it is no more than 12 hours after you should have given it.

 Never give a double dose of tacrolimus.

What if I give too much?

 It can be dangerous to give too much tacrolimus. If you think you may have given your child too much tacrolimus, contact your doctor or local NHS services (see end of leaflet) or take your child to hospital.

Take the medicine container or packaging with you, even if it is empty. This will be useful to the doctor. Have the packaging with you if you telephone for advice.

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects).

Side-effects you must do something about

 If your child gets a skin rash, spots or itching, has problems breathing or seems short of breath or is wheezing, or their face, throat, lips or tongue start to swell, they may be allergic to tacrolimus. Take them to hospital or call an ambulance straight away.

 If your child has pain when passing urine (doing a wee) or produces less urine than usual, contact your doctor, transplant specialist or nurse straight away, as your child may have a kidney problem.

Other side-effects you need to know about

- Your child may get diarrhoea, indigestion, feel sick or be sick (vomit). These effects usually wear off when your child's body is used to the medicine. If they are still a problem after a week, contact your doctor, transplant specialist or nurse.
- Your child may get dizzy, seem confused, anxious or depressed and may have difficult sleeping.
- They may have blurred (fuzzy) vision or hearing problems.
- They may get muscle cramps and pains in the joints.
- They may lose some hair but this will grow back when the medicine is stopped.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor.

Can other medicines be given at the same time?

- You can give your child medicines that contain paracetamol, unless your doctor has told you not to.
- You should not give your child medicines that contain ibuprofen.
- Tacrolimus should not be taken with some common drugs that you get on prescription. It is important to tell your doctor and pharmacist that your child is taking tacrolimus and check **before** giving any other medicines. This includes herbal or complementary medicines.

Is there anything else I need to know about tacrolimus?

 Because tacrolimus weakens the body's immune system, your child will be more prone to infection. If they have a fever (temperature above 38°C) or seem unwell, contact your doctor straight away.

 It is important that your child always takes the same brand of tacrolimus. Make a note of which brand your child has, and check that you are given the right one each time you get a new supply.

 Your child should not eat grapefruit or drink grapefruit juice, as this may increase the level of tacrolimus in the body, which could be harmful.

- The amount of tacrolimus that your child has (the dose) will be worked out by the hospital staff. They will take blood samples regularly to check tacrolimus levels.
- Do not change the amount that you give your child unless your doctor tells you to.
- Your child has an increased risk of getting skin cancer while taking tacrolimus. To protect their skin, they should wear clothes that cover their body, arms and legs, use high-factor sunscreen, and avoid going out in strong sunlight.

General advice about medicines

- Only give the medicines to *your* child. Never give it to anyone else, even if their condition appears to be the same, as this could do harm.
-  If you think someone else may have taken the medicine by accident, contact your doctor straight away.
- Make sure that you always have enough medicine. Order a new prescription at least 2 weeks before you run out.
 - Make sure that the medicine you have at home has not reached the 'best before' or 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

Where should I keep this medicine?

- Keep the medicine in a cupboard, away from heat and direct sunlight.
- Keep the medicine in the container it came in.
- Make sure that children cannot see or reach the medicine.

Who to contact for more information

Your child's doctor, pharmacist or nurse will be able to give you more information about tacrolimus and about other medicines used to prevent transplant rejection.

You can also get useful information from:

England NHS 111: 111 - www.nhs.uk

Scotland NHS 24: 111 - www.nhs24.com

Wales/Galw Lechyd Cymru NHS Direct: 0845 4647 - www.nhsdirect.wales.nhs.uk

Northern Ireland NI Direct: www.nidirect.gov.uk

Transplant Kids - www.transplantkids.co.uk

www.medicinesforchildren.org.uk