



Tacrolimus for nephrotic syndrome

This leaflet is 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 adults. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

- Make sure you always have the same brand of tacrolimus.
- Do not stop giving tacrolimus as this may make your child unwell.

Name of drug

Tacrolimus

Brand names: Adoport, Prograf, Modigraf (granules)

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

Nephrotic syndrome affects the kidneys. Proteins from the blood leak into the urine. This is thought to be caused by the immune system. Tacrolimus is an immunosuppressant – it makes the immune system less active. It may be prescribed if your child has had several relapses of nephrotic syndrome.

What is tacrolimus available as?

- Capsules (Adoport, Prograf): 0.5 mg, 0.75 mg (Adoport), 1 mg, 2 mg (Adoport) 5 mg; these may contain small amounts of lactose
- Granules (Modigraf): 0.2 mg and 1 mg sachets

When should I give tacrolimus?

- Tacrolimus is usually given **twice each day**. This should be 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.
- Give the medicine at about the same time each day so that this becomes part of your child's daily routine, which will help you to remember.
- If your child is having blood taken to measure the level of tacrolimus, make sure their evening dose is 12–14 hours before the time of the blood test.

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.



Capsules should be swallowed whole with a glass of water, squash or milk. Your child should not chew the capsule.



Modigraf granules

- Do not use plastic cups or spoons, as the granules will stick to them.
- Cut open the correct number of sachets with scissors, one at a time, and tip the contents into a small glass or cup. Tap the sachet to get the granules out but you do not need to scrape them out.
- Add at least 0.4 mL of water for each 0.2 mg sachet or 2 mL for each 1 mg sachet. You can measure these amounts with an oral syringe.
- Stir the mixture until the powder is dissolved.
- Your child should drink all the mixture straight away or you can give it to them using a spoon or oral syringe.
- Add the same amount of water as used above to the glass or cup and swirl it around. Your child should drink all the mixture straight away. This is to make sure they get the whole dose.
- Do not use more than 50 mL of water for the two steps.

When should the medicine start working?

The medicine starts to work immediately but you will not see any difference in your child. It may take a few weeks to prevent relapse of nephrotic syndrome. It is important to continue giving tacrolimus as your doctor has told you to.

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 specialist hospital team.

What if I forget to give it?

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.



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, contact your doctor or local NHS services (details at end of leaflet) for advice. 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.



If your child has pain when passing urine (doing a wee) or produces less urine than usual, contact your doctor or nurse straight away.

Other side-effects you need to know about

- Your child may get diarrhoea, indigestion or 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 difficulty sleeping.
- They may have blurred (fuzzy) vision or hearing problems.
- They may get muscle cramps or pains in the joints.
- They may lose some hair.
- There may sometimes be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at mhra.gov.uk/yellowcard.
- More information on side-effects can be found in a [leaflet](#) on our website.

Can other medicines be given at the same time as tacrolimus?

- 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 medicines that you get on prescription. Tell your doctor and pharmacist about any other medicines your child is taking before giving tacrolimus.
- Check with your doctor or pharmacist before giving any other medicines to your child. This includes herbal and complementary medicines.

Is there anything else I need to know about tacrolimus?

- Your child will be more prone to infection because tacrolimus suppresses the immune system. If your child has a fever (temperature above 38°C) or seems unwell, contact your doctor straight away.
- Your child must always have the same brand of tacrolimus. Keep a note of which brand this is, 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.
- Tacrolimus may increase the risk of skin cancer. Your child should avoid strong sunlight. Protect their skin with clothing and high-factor sunscreen (at least SPF 50).
- Tacrolimus is also used to prevent the rejection of transplanted organs. Information in the public domain may relate to this use, rather than nephrotic syndrome.

General advice about medicines

- Only give this medicine to your child. Never give it to anyone else, 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 '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 the container it came in, in a cupboard, away from heat and direct sunlight.
- 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 other medicines used to treat nephrotic syndrome. You can also get useful information from:

England: NHS 111	Tel 111 nhs.uk
Scotland: NHS 24	Tel 111 nhs24.scot
Wales: NHS 111 Wales	Tel 111 111.wales.nhs.uk
Northern Ireland: NI Direct	nidirect.gov.uk
Kidney Care UK	01420 541424 kidneycareuk.org
National Kidney Federation	0800 169 09 36 kidney.org.uk

www.medicinesforchildren.org.uk

