



# Medicines after transplant

This leaflet explains about the medicines needed after a kidney transplant, how you should take them and what possible side effects may happen. If you have any questions, please call the team at Great Ormond Street Hospital (GOSH) on 020 7813 8172. During evenings and weekends, call Eagle Ward on 020 7405 9200 ext 5103.

Once you have had your kidney transplant, you will need to take medicines regularly. The most important of these medicines are the ones that 'damp down' your immune system to stop your body attacking your new kidney. These are called 'immunosuppressants'. You will also need to take medicine to stop your blood forming clots, called anti-coagulants. If you develop an infection, you might need antibiotics, or if your blood pressure is high, you might need to take anti-hypertensive medicine. Some medicines may only be needed for short periods of time, but you will need to take others for as long as your new kidney is working.

## Following your medicine schedule

It is vital that you take all of your medicines at the right dose and at the right times. Not taking your medicines, even missing one dose, could lead to serious illness and the loss of your kidney. In fact, the most common reason for young people losing a transplanted kidney is not taking the immunosuppressant medicines as prescribed. Each year, at least one patient at GOSH loses a kidney for this

reason. If you are struggling with your medicine schedule, please talk to us sooner rather than later so that we can help you. You can come to GOSH to see us or we can ring you when convenient.

## General guidance

- **Never run out of your tablets!**
- Keep all medicines, tablets and capsules in a safe place where children cannot reach them. Store them in a cool, dry place away from direct sunlight or heat.
- You should handle some of these medicines with care, particularly the immunosuppressant ones. Avoid contact with your skin or eyes and follow our guidelines Special handling of immunosuppressant medicines information sheet.
- Some of these medicines need careful monitoring, so you will need regular blood tests which will be done at your regular clinic appointments.
- The use of some medicines for children and young people is not licensed in the UK. Medicines are often used outside of their licence (off label) in children and young people because trial data is not available.

- Some medicines react with other medicines, altering how they work. Always check with your doctor or pharmacist before taking any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.
- If you are sexually active you must make sure you are using an effective method of contraception. Using condoms or another barrier method in addition is recommended as this will reduce the risk of catching sexually transmitted infections (STIs), which can be harder to fight off when you are taking immunosuppressant medicines. If you think you may be pregnant tell your family doctor (GP) and telephone the team at GOSH immediately. Keep taking your medications unless told not to.
- You shouldn't have any live immunisations while taking immunosuppressant medicines. We will usually have given you all the routine ones during preparation for transplant, but please talk to us if you need immunisations to go abroad. More information about immunisations is in our *Kidney transplant operation and afterwards* booklet.
- If your doctor decides to change these medicines or they pass their expiry date, please return them to your pharmacist. Do not flush them down the toilet or throw them away.
- If you vomit after taking a dose, please call the team to check whether you need to take another one. Do not take another dose without checking.
- If you forget to take a dose, do not take a double dose. Tell your doctor

or nurse and stick to your regular medicine schedule.

## Dealing with aches and pains

We all get discomfort from time to time, whether it's a sprained ankle or period pains. When you have had a kidney transplant, you can take pain relief medicines when needed, but only paracetamol. Ibuprofen is not recommended after transplant. Remember if you have any questions about pain relief, please contact us.

## Information about specific medicines

### Prednisolone

This is a steroid – a hormone (chemical messenger) that is produced naturally in the body by the adrenal glands and reproductive organs. There are many different types of steroid but the one most commonly used in kidney conditions is prednisolone, a corticosteroid. Your daily dose will be gradually tapered or reduced during the eight weeks following transplant until you reach your 'maintenance' dose.

### How is it taken?

Prednisolone is usually taken by mouth in the form of tablets in 1mg, 5mg and 25mg strengths. Soluble tablets in 5mg strength are also available. Steroids are best taken at the same time each day with food (usually in the morning). People taking steroids twice a day may have difficulty in sleeping if they take their second dose too late in the evening so make sure you have your second dose by late afternoon.





## What are the side effects?

- **Changes in behaviour** – You may feel irritable, have mood swings or lose your temper easily. This effect is usually temporary.
- **Weight gain** – You may have an increased appetite, which means you will feel hungrier than usual so might eat more and then gain weight. Keeping to a well balanced diet may help. Talk to our dietitian if you're worried. Your face may appear more chubby than usual, particularly after long-term steroid treatment. If you have put on a lot of weight, you may develop stretch marks, especially on your tummy and thighs.
- **Irritation of the stomach lining** – These medicines are best taken with meals or after food to reduce any stomach irritation.
- **High blood pressure** – You may have headaches or feel dizzy. We will check your blood pressure regularly while you're taking steroids. If your blood pressure becomes high, we may suggest that the steroid dose is split in half and you take it twice a day.
- **Alteration in blood sugar level** – Steroids may cause a temporary increase in blood sugar levels. Some signs of a raised blood sugar level are thirst and needing to pass more urine than usual.
- **Effect on growth and/or thinning of bones** – If taken over a long period of time or at a high dose, your growth may be affected and/or your bones may become thinner. We will monitor you closely to reduce the chance of these side effects.
- **Skin** – Steroids may cause acne on the face, chest and back. Please talk

to us before you take any medicines to treat acne. Steroids may also cause rosy cheeks, sensitive skin and stretch marks.

### Important information about prednisolone

If you have been on steroids for more than a few weeks and become unwell or need to have an operation, your natural production of steroids (which helps you respond to a stressful situation) will be reduced. You may need a short course of additional steroids to cover this period.

**Remember to carry your steroid card with you all the time so that if anything happens to you, people will know that you are taking steroids regularly.**

## Tacrolimus

This is a strong immunosuppressant medicine. We will need to measure the amount of this medicine in your blood very carefully so we are sure we are giving you the right dose. A dosage that is too high or too low can affect how the kidney functions, so we may alter the dose from time to time.

### How is it taken?

Tacrolimus is taken by mouth in the form of capsules, as granules that are made up into a suspension, or as a suspension (not currently licensed in the UK so may not be readily available).

Tacrolimus is available as 0.5mg, 1mg, 5mg capsules under the brand name Prograf®. You should swallow these whole with water, on an empty stomach (one hour before or two hours after food). This is because the absorption of tacrolimus is best when

there is no food in the stomach. The dose is taken twice a day, morning and evening. If you cannot take tacrolimus at the advised times, make sure that you take the doses at the same time each day with respect to food so that your blood levels of the drug are interpreted correctly.

Tacrolimus is also available as 0.5mg, 1mg, 3mg, 5mg capsules called Advagraf®. These capsules are taken once a day in the morning but you will only be prescribed this preparation if your doctor thinks it is suitable for you.

You may be prescribed granules that can be made into a suspension. These are branded Modigraf® and are available as 0.2mg and 1mg granules for oral suspension. You must open the correct number of sachets and mix the contents with water to make a suspension. Stir or swirl gently until the granules have been suspended completely. You can then draw up the suspension with an oral syringe or swallow directly. The dose is taken twice a day, morning and evening. If you cannot take tacrolimus at the advised times, make sure that you take the doses at the same time each day with respect to food so that your blood levels of the drug are interpreted correctly.

A suspension is available as a 'special' for children unable to take the capsules or granules. A 'special' is an unlicensed medicine that has to be prepared for individual patients so may not always be readily available. We want to make sure that the amount of medicine absorbed is always the same and that there is no mix-up between mg and mls, so ask your pharmacist to supply the tacrolimus suspension as 5mg in

5mls made by the Specials Laboratory. We will give you an availability letter outlining this, which you can give to your pharmacist.

## What are the side effects?

### ■ Upset stomach

### ■ Alterations in liver function –

Tacrolimus may cause mild changes to your liver function. Blood tests will be needed on a regular basis to check the liver is working well

### ■ High blood pressure – This will be checked on a regular basis

### ■ Mild shakes – If you develop shakes or tremors, please tell your doctor as the dose of tacrolimus may be too high and need to be changed.

### ■ Sensitivity to sun – Avoid excessive exposure to the sun. When you go outside, always make sure that you use an effective sunscreen or lotion and wear a hat.

### ■ Glucose intolerance – Tacrolimus may cause a temporary increase in blood sugar levels. Some signs of a raised blood sugar level are thirst and needing to pass more urine than usual.

### ■ Alteration in kidney function – Tacrolimus may cause mild changes to your kidney function. Blood tests will be needed on a regular basis to check how well your kidneys are working.





### **Important information about tacrolimus**

Tacrolimus can react with grapefruit and grapefruit juice. It should not be given at the same time as grapefruit juice or any drinks containing it. It should also be avoided for one hour before and after each dose.

The person writing the prescription must always specify the brand. Always make sure that you know the preparation of tacrolimus you should be taking and that your doctor prescribes the Prograf® brand of capsules if you are on a twice daily dose, the Modigraf® brand if you are taking the granules for oral suspension, the Advagraf® brand if you are suitable for the once a day dose or the 'special' tacrolimus 5mg/5ml suspension. At the moment you should not be prescribed or supplied with any other brands of tacrolimus.

## **Azathioprine**

This is also an immunosuppressant

### **How is it taken?**

It is given by mouth, in the form of tablets or liquid, once a day. The liquid used at GOSH is not currently licensed in the UK and is a 'special'. A 'special' is an unlicensed medicine that has to be prepared for individual patients so may not always be readily available. We want to make sure that the amount of medicine absorbed is always the same and that there is no mix-up between mg and mls, so ask your pharmacist to supply the azathioprine liquid as 50mg in 5mls. We will give you an availability letter outlining this, which you can give to your pharmacist.

### **What are the side effects?**

- **Allergic reaction** – Some people taking azathioprine have an allergic reaction to the drug. This reaction may be mild to severe. Signs of a mild allergic reaction include skin rashes and itching, high temperature, shivering, redness of the face, a feeling of dizziness or headache. If you see any of these signs, please report them to a doctor or nurse. Signs of a severe allergic reaction include any of the above, as well as shortness of breath.
- **Alteration in blood count** – Azathioprine can affect your blood, although this is rare. If you have fewer red blood cells than normal, you could develop anaemia. Symptoms of anaemia include tiredness, lethargy and paleness. If you have fewer white cells than normal, you could catch an infection more easily than usual. If you have a lower number of platelets than usual, you could bruise easily. If you notice any unexplained bruising, bleeding, sore throat, temperature or other signs of infection, please contact your family doctor (GP) or local paediatrician for a blood test immediately.
- **Alteration in liver function** – Azathioprine can cause some mild changes to your liver function but this will be monitored by regular blood tests.
- **Nausea and vomiting** – These symptoms can be reduced by starting with a low dose of azathioprine and increasing it over time. Taking the medicine after meals can also help.
- **Damage to the unborn baby** – Azathioprine must not be given to patients who may be pregnant or

are likely to become pregnant in the near future. If you are female and ten years old or older, we will ask you about your periods and any possibility that you could be pregnant. If you are sexually active, you must use a reliable form of contraception.

## Mycophenolate mofetil (MMF)

Mycophenolate mofetil (MMF) is an immunosuppressant, which may be used instead of azathioprine. If MMF causes an upset stomach, the dose can be split and given three or four times daily as this is better tolerated. MMF capsules or tablets are available in several brands but you don't need to worry if you are prescribed or dispensed a different brand to normal.

### How is it given?

MMF is taken by mouth in the form of capsules, tablets or an oral suspension.

### What are the side effects?

- **Nausea, vomiting, abdominal pain and diarrhoea** – These symptoms can be reduced by starting with a low dose of MMF and increasing the dose gradually over time or increasing the number of times the medication is given each day.
- **Alteration in blood count** – MMF can affect your blood, although this is rare. If you have fewer red blood cells than normal, you could develop

anaemia. Symptoms of anaemia include tiredness, lethargy and paleness. If you have fewer white cells than normal, you could catch an infection more easily than usual. If you have a lower number of platelets than usual, you could bruise easily. If you notice any unexplained bruising, bleeding, sore throat, temperature or other signs of infection, please contact your family doctor (GP) or local paediatrician for a blood test immediately.

- **Damage to the unborn baby** – MMF must not be given to patients who may be pregnant or are likely to become pregnant in the near future. If you are female and ten years old or older, we will ask you about your periods and any possibility that you could be pregnant. If you are sexually active, you must use a reliable form of contraception.
- **Sensitivity to sun** – Avoid excessive exposure to the sun. When you go outside, always make sure that you use an effective sunscreen or lotion and wear a hat.

---

Compiled by the Renal and Pharmacy teams  
in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Foundation Trust  
Great Ormond Street  
London WC1N 3JH

[www.gosh.nhs.uk](http://www.gosh.nhs.uk)

