

Patient information

Your guide to managing medication after a kidney transplant

Second edition April 2017



Introduction

The information here will help you understand your treatment and monitoring that you will receive from the kidney specialists. You can contact the specialists for advice should you have any question.

Contact details

In the event of an emergency, please dial 999 immediately.

If you are unwell you can contact the transplant clinic for advice during weekdays, or ward 9E at any time. You may be advised to attend Accident and Emergency (A&E), or the Renal Assessment Unit (RAU) where appropriate.

You can also contact your GP as usual for advice or to be seen. Please inform GP reception that you are a kidney transplant patient.

Barts Health NHS Trust has a Medicines Information helpline for patients who have questions about the medication they have been given (<u>not</u> prescription, supply or clinic appointments).

Transplant Clinic reception	020 3594 1651 or ending 1652 / 1653 / 1654	Monday to Friday 9 am - 4 pm for appointment queries
Transplant nursing team	020 3594 0144	Monday to Friday 8 am - 6 pm
Renal pharmacist	020 3246 0134 or bleep 1328 via hospital switchboard: 020 7377 7000	Monday to Friday 9am - 5pm
Renal dietician	020 3594 1101	Monday to Friday 8:30 am - 4:30 pm
9E Ward	020 3594 2614	24 hours
9F Ward	020 3594 2635	24 hours
Medicines information helpline	020 8535 6971	Monday to Friday 9 am - 5 pm

Transplant Medicines

Immunosuppressants

Following your kidney transplant, your body's immune system will try to reject the new organ. Although you may have had a series of tests before your transplant to ensure the match between your body and the new kidney is as close as possible, the donor tissue will not be identical to yours. Hence, immunosuppressants are used to reduce your body's immune response to prevent your body from rejecting the new kidney (also known as anti-rejection medicine).

The type of donor and individual patient characteristics will be used to determine the immunosuppression regimen prescribed to you. This will usually consist of the following three medicines:

- 1. Tacrolimus (Adoport® brand only) or Ciclosporin (Deximune®)
- 2. Mycophenolate mofetil (MMF) or azathioprine
- 3. Prednisolone

Immunosuppressants are medications for life to prevent rejection. They can only be started by the kidney specialist who will advise you for the first time on their benefits outweighing the risk. You must never stop taking these medications unless you have been told to do so by the transplant team.

Take your medication correctly

You will need to understand and take your immunosuppressants at the exact dose and time prescribed to you. Following your transplant, a member of the renal pharmacy team will issue a medication record sheet and go through the medicines with you. The card will guide you how best to take your medicines when you go home. For example, take tacrolimus (Adoport®) at 10 am and 10 pm consistently.

You will start taking your medications (i.e. self-medication) on the ward using the medication record sheet with the help of the nurses. The nurse will check that you have chosen the right medicine and dose before you take them. The nurse will also inform you of any dose changed by the doctor. This process allows you to see the changes in your medications whilst in hospital as you will need to follow instructions on dose changes made in the outpatient transplant clinic when you are at home.

Just before your discharge the nurse will go through the medications prescribed on the discharge letter with you and confirm the doses. The nurse will use the discharge letter as a checklist to ensure all medicines are put in your medicine bag (including any fridge items).

Record Keeping

The kidney specialist will be solely responsible for prescribing (and adjusting the doses of) your immunosuppressants and valganciclovir (if you are prescribed this treatment). Other medications (e.g. antihypertensives, insulin, etc) can be changed

by the kidney specialist, GP, your local hospital, outpatient clinics or specialist nurses (e.g. heart failure nurse, diabetes nurse in the community). Royal London Hospital will not be aware of these changes. It is therefore important that you keep a record of any change from any source, and let us know when you attend the transplant clinic, and/or are admitted to the hospital.

Medicines and doses can sometimes be difficult to remember especially when they are changing. We advise that you carry the most updated medication list with you at all times. This is because you may be too unwell to speak to the doctor. The list can provide important information to the first attended doctor in an event of an emergency.

A simple way to keep up with the change is to set up your own medical record folder. This will keep all hospital discharge letters and outpatient clinic letters.

Following each hospital discharge, you should see your GP for further supply before your medicines run out (except immunosuppressants and valganciclovir which will be prescribed by the transplant clinic). You can show your GP the discharge letter but ensure that you always keep a copy for yourself. Your GP should have received a copy sent electronically by the hospital on the day of your discharge. This will allow your GP to update your record following each hospital discharge.

Take the correct brand of tacrolimus or ciclosporin

There are many tacrolimus and ciclosporin brands on the market. You should only take the brand prescribed to you by the kidney specialist:

- Adoport[®] (twice daily brand of tacrolimus) or
- Deximune® (twice daily brand of ciclosporin)

Different brands and preparations will not have the same effect in protecting your kidney. It is important that you only take the brand prescribed to you by the kidney specialists. If you received a different brand and have not been informed of the change please contact the transplant clinic immediately.

Do not miss a dose

Do not double the dose to make up for a forgotten dose. For example, if you have forgotten to take your Adoport® wait until it is time for the next dose, and then continue as before.

If you forget to take a dose, you should take it as soon as you remember as long as there is at least six hours interval left before the next dose.

Always inform the kidney specialist of any missed doses the next time you attend the transplant clinic.

Taking other medications

Always check with the transplant clinic, GP or dentist or pharmacist (hospital or community) before buying any over the counter medicines. This is to prevent any interactions with the medicines you are taking.

Complementary medicines (herbal remedies)

We do not recommend the use of complementary or herbal remedies following your transplant. This is because little is known of their effect on your condition and the treatment you are receiving. Some herbal remedies are known to interact with your immunosuppressants leading to toxicity and kidney rejection. The risk of rejection outweighs the benefits of taking these remedies. You can contact the Medicines Information service for advice if required.

Persistent diarrhoea and/or vomiting

If you are unable to keep your medication down (due to vomiting), or your body is not able to absorb them (due to diarrhoea), the level of immunosuppressants in your blood may change. This may increase the risk of rejection.

You should contact the transplant clinic if vomiting or diarrhoea lasts more than 24 hours. If this takes place outside normal working hours, please contact ward 9E. You may be asked to come into hospital for fluids with your regular medicines given into your vein through a drip if needed.

Infections

You are more likely to get an infection whilst on immunosuppressants. This is because immunosuppressants will reduce your body's ability to fight infections and make you more prone to certain infections.

Avoid crowded places. This will avoid close contact with people who may be unwell.

Instil good hygiene such as washing hands thoroughly with soap and water.

Avoid cleaning pet cage, litter tray or fishbowls.

Skin protection

Immunosuppressants may increase your sensitivity to the sun, and make you more at risk of skin cancer.

Avoid sun beds (no sun bathing). Use high sun protection factor cream (SPF 50) and wear protective clothing to also cover your head, neck, arms and legs (hat, long sleeves) in sunny weather.

You should check your skin regularly for any changes e.g. lumps, unusual spots, moles, or warts on your skin. Report any changes immediately.

Mouth

Some of your medicines may affect your gums. You should therefore keep your teeth and gums clean and healthy.

We advise that you visit your dentist once a year. Tell your dentist that you are a kidney transplant patient and that you hold a steroid card. Do not forget to inform your dentist of any allergy.

Contraception

Two reliable forms of contraception should be used at the same time.

Condoms are safe and protect you from sexually transmitted diseases but are not always reliable on their own. A second method of contraception should be used at the same time.

The combined contraceptive pill is safe for most women, but it may increase your blood pressure. It is important that you inform the doctor if you are on the pill so that your blood pressure can be monitored carefully. Such contraception should be avoided if you have a past history of blood clots.

For women, a yearly smear test is recommended at your GP practice. You should self-check your breasts for any swelling, lumps (including under your arm) and discharge from the nipples regularly.

For men, you should self-check for any swelling or lumps in your testicles regularly.

Pregnancy and breastfeeding

Please speak to specialist at the transplant clinic if you are planning to start a family. It is important that you are well enough before some changes can be made to your medications to make it less toxic to the foetus. Some medications are known to cross the placenta and harm the unborn baby during pregnancy. Others can be excreted in the breast milk, affecting the baby when breastfed. In men, some medications may be transferred via seminal fluid to their partners. Hence, two reliable forms of contraception mentioned above should be used.

Vaccinations

You should have a flu vaccine once a year at your GP practice to protect yourself from any complications (e.g. rejection) brought on by a chest infection.

Live vaccines should be avoided after transplant and/or if you are on dialysis due to risk of re-infection. This is because live vaccines contain attenuated (weakened) organism which work by mimicking a natural infection to boost antibodies.

Public Health England advised that those in regular close contact with you should be vaccinated against varicella (shingles) and influenza. This is to minimise your risk of contracting these infections where only live vaccines are available which you are not able to have.

Common live, attenuated vaccines to be avoided

MMR (Measles, Mumps and Rubella)	MMRVAXPRO®, Priorix®
BCG (Bacillus Calmette-Guerin)	Bacillus Calmette-Guerin vaccine
Oral Polio	Sabin®
Yellow fever	Arilvax®, Stamaril®
Oral Typhoid	Vivotif®
Varicella-zoster	Varilix®, Varivax®
Herpes zoster (shingles)	Zostavax®
Intransal influenza vaccine	Fluenz®

You can have the inactivated vaccines although their effect on you may be reduced. Hence, further booster doses may be required according to antibody levels in your blood.

Common inactivated vaccines

Common macritated vaccines	
Adsorbed Diptheria, Tetanus &	Revaxis®
Inactivated Poliomyelitis	
Polio Inactivated	Salk®, IPV®
Haemophilus influenza type b (Hib) &	Menitorix®
Meningococcal group C conjugate	
Influenza	Split Virion, Surface Antigen
Pneumococcal	Pneumovax II®
Meningococcal group C conjugate	Meningitec®, Menjugate Kit®, NeisVac-C®
Meningococcal Polysaccharide A, C,	ACWY Vax®
W135 and Y	
Hepatitis A	Avaxim®, Havrix Monodose®, Epaxal®
Hepatitis B	Engerix B®, Fendrix®, HBvaxPRO®
Hepatitis A & B	Twinrix®
Hepatitis A & Typhoid	Hepatyrix®, ViATIM®
Typhoid Vi Capsular Polysaccharide	Typherix®, Typhim Vi®
Tick-Borne Encephalitis	FSME-IMMUN®
Rabies	Rab®, Rabipur®
Anthrax	Anthrax
Cholera	Dukoral®

Overseas travel

We advise that you do not travel overseas for the first 12 months after a kidney transplant. This is because you will be attending the transplant clinic frequently for close monitoring. Your immunity will be considerably lower than normal and you will need access to kidney specialist unit.

Always check that you are fit to travel. A minimum of <u>six-week notice period</u> is required to ensure:

 Your GP is given sufficient time to arrange a vaccination programme suitable for you and your destination of travel. In some cases, there may not be any

- inactivated vaccines available for you. Further advice from a travel specialist may be needed.
- Some travel medicines may need to be started 4 weeks before you enter the country to be effective, these include antimalarial medicines.
- Blood tests and dose adjustment of your transplant medicines may be needed should there be any 'medicine-to-medicine' interactions and/or 'medical condition-to-medicine' interactions.
- A travel letter should be obtained detailing relevant medical history, list of current medication, and kidney specialist contact details. The letter is a compulsory document should you be travelling with liquid medicine more than 100ml per container via the airport.

You will need to carry your medications in your hand luggage. We recommend that you also carry an additional 2 weeks supply to cover any unexpected delays.

It is important that you do not book your holiday until you have taken out holiday insurance which covers you for a 'pre-existing medical condition'. Most standard insurance do not provide this cover. Please visit www.kidney.org.uk (Kidney Patients Association) for helpful tips.

If you are travelling to Europe, you should also carry a European Health Insurance Card (EHIC) in addition to the correct holiday insurance.

You will be entering an overseas country at your own risk should you fail to arrange a transplant clinic appointment at least six weeks before your planned departure date.

Driving

You should check with transplant clinic to ensure that you are fit to drive. You should also contact your insurer to check if you are insured to drive after the operation.

Do not drive or use any tools or machines if you feel dizzy or have problems seeing clearly after taking tacrolimus. These effects are more frequently observed if tacrolimus is taken with alcohol.

Monitoring you while you are taking immunosuppressants

You will be seen at the transplant clinic three times a week (Monday, Wednesday and Friday) to have your progress checked. Your first clinic appointment will be held prior to your discharge from the ward. This will be reduced gradually to twice a week and eventually aiming for once a month by the end of your first year.

You will have more regular blood tests initially to check how the new kidney is progressing, your response to treatment and any adverse effects. At the clinic, tacrolimus or ciclosporin blood level will be checked and re-dosed. You are required to keep up to date of the new doses.

The dose required varies from one person to other. If the level is too low, your immune system may start to attack (reject) the kidney. On the other hand, if the

level is too high, you will be more prone to infection, side-effects and toxicity. We aim to achieve the right level, high enough to prevent rejection but without causing undue side-effects.

As a general rule, higher levels are aimed for initially. A lower level will be aimed for over time once you are stabilised.

Rejection is more likely to happen in the first three months. You can help by telling us if any of the following happens:

You pass less urine

You put on weight quickly (It is good to keep a record of your weight)

Your ankles are swollen

You feel dizzy or light headed

Immunosuppressants can also affect liver and kidney function, blood pressure and composition of the blood. Refer 'glossary of blood tests' on **page 26** for better understanding of your tests.

Supply of medicines

Any missed doses of your medications will increase the risk of kidney rejection. Therefore it is important that you do not run out of a supply.

You should obtain a supply of all medicines from your GP 2 weeks before they run out (except immunosuppressants and valganciclovir which come from the hospital). Some local chemists may not stock some of your medicines routinely. This will allow time for your local chemist to order them in before you run out. The hospital pharmacy (pharmacy in hospital premises) will not accept GP's FP10 prescription.

All immunosuppressants and valganciclovir will be supplied by the hospital only. The transplant clinic will advise you on the available options for future supply.

Always keep all strengths of tacrolimus (or ciclosporin) that will have been proved to you on discharge from the hospital as you may be informed of a dose change by the transplant clinic over the phone following your clinic appointment.

Eligibility for free prescriptions.

Transplant patients are not entitled to free prescriptions unless you qualify under the criteria set by the NHS. For more information please visit www.nhsbsa.nhs.uk or speak to your local community pharmacy.

If you are not entitled to free prescriptions speak to your local community pharmacy about pre-payment certificates or visit http://www.nhsbsa.nhs.uk/ppc.

Tacrolimus

Barts Health NHS Trust uses Adoport® brand only. You must remain on the same brand of this immunosuppressant lifelong. If you are given a different brand, please contact the transplant clinic or ward 9E after working hours immediately.

Adoport® is available in strengths below:

- 0.5 mg capsules (white/ivory)
- 0.75 mg capsules (light green)
- 1 mg capsules (white/brown)
- 2 mg capsules (green)
- 5 mg capsules (white/orange)

You will only be supplied 0.5 mg, 1 mg, 2 mg and 5 mg capsules on discharge. You will be advised the dose on the number of milligrams (not number of capsules).

You must check the strength of the capsules before swallowing the correct dose. For example, any wrong strength (between 0.5 mg and 5 mg capsules) may result in ten times more than the intended dose. There is no antidote in an event of an overdose. Please contact the transplant clinic or ward 9E if after working hours as soon as possible if you have taken the wrong dose.

The transplant clinic may wish to prescribe other strengths for you in the future. This will depend on your dose following the blood test.

How do I take tacrolimus?

- Swallow whole with a glass of water.
- On empty stomach (i.e. no food in stomach) at least one hour before food (or at least two hours after food) consistently. Fatty food can both slow down and reduce the absorption of tacrolimus.
- Take same time each day, 12 hours apart at 10 am and 10 pm consistently.
- On transplant clinic days, do not take the morning dose at home but bring some supply with you. Take the dose <u>immediately after the blood test</u>. Do not wait till you get home as this will be too near to your second dose at 10pm. The second dose should be taken at 10 pm as usual.
- No grapefruit (including juice or any grapefruit containing products), Seville orange (often found in some marmalade) and pomelo. They can increase the amount of tacrolimus in your bloodstream unnecessarily and lead to toxicity.
- Check labels of juices, juice blends, fruit drinks, sodas and marmalades for these ingredients.
- Avoid herbal remedies. Some herbal products e.g. St John's Wort (hypericum perforatum) are known to affect the effectiveness of tacrolimus.

Side-effects

Like any medicine (or even food you take), tacrolimus may cause some unwanted effects. Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are;

- Tacrolimus increases your blood sugar and your risk of developing diabetes following your transplant.
- Increased potassium levels
- Increased blood pressure
- You may become shaky if the level of tacrolimus in your blood is very high.
- Nausea or diarrhoea, if you develop vomiting or diarrhoea that lasts longer than a day please contact the transplant team for advice.

Let the transplant team know if you suffer any of the above or anything unusual.

Mycophenolate mofetil

Mycophenolate mofetil is available as either a 500 mg tablet or 250 mg capsule. Mycopenolate mofetil is also referred to as 'MMF'. The brand supplied to you by Barts Health NHS Trust may change but there is no need to worry. This is because the bioavailability (the amount of drug that is released into your body) is approximately the same for all brands. This will not have an impact on your transplanted kidney.

You will only be supplied 500 mg tablets on discharge. You will be advised the dose on the number of milligrams (not number of tablets). Please contact the transplant clinic or ward 9E if after working hours as soon as possible if you have taken the wrong dose.

The transplant clinic may wish to prescribe other strengths for you in the future if a lower dose is needed.

How do I take mycophenolate mofetil?

- Swallow whole with a glass of water. Do not break, crush or chew tablets.
- Take same time each day, 12 hours apart at 10 am and 10 pm consistently.
 Food has no effect on MMF, so you are advised to take at the same time as tacrolimus to reduce the number of times you have to take your medicines a day.

Side-effects

Like any medicine (or even food you take), MMF may cause some unwanted effects. Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are:

- You may experience some stomach cramps, diarrhoea or sickness. Changing the dose sometimes can help with this.
- This drug suppresses your bone marrow which mean you may have a lower white cell count, anaemia or lower platelet count which will make you more vulnerable to infection. You will have regular blood tests to monitor for this.

Skin cancer

There is an increased risk of skin cancer with use of MMF but its benefits as an immunosuppressant outweighs its risk. Refer to earlier 'skin protection' on page 6

Birth defects and spontaneous abortion

MMF is associated with a high rate of serious birth defects and spontaneous abortion compared to other immunosuppressants. If a pregnant women is exposed to mycophenolate mofetil, either by taking it herself or through unprotected sex with a man taking this medicine, it could cause a miscarriage or birth defects in her child.

Both men and women should understand the risk of harm to a baby. Effective contraception is essential to prevent the risk to your baby.

Information for women.

Women of childbearing potential should use two forms of effective contraception before starting MMF, during treatment and for 6 weeks after stopping MMF.

You must also not stop taking MMF should pregnancy occur but should speak to your transplant team.

Information for men.

Men (including those who have had a vasectomy) should use condoms during treatment and for at least 90 days after stopping MMF.

Female partners of male receiving MMF should use highly effective contraception during treatment and for 90 days after their partner has taken his last dose.

If you think your partner might have become pregnant while you were taking mycophenolate mofetil, or within 90 days after your last dose, talk to your doctor immediately who will advise you both what to do.

Do not donate sperm while taking mycophenolate mofetil and for at least 90 days after your last dose.

Information for men and women.

If you plan to have a baby speak to your doctor about this. It is very important that you do not stop taking mycophenolate mofetil without speaking to your doctor. Your transplant may be rejected if you stop taking mycophenolate mofetil.

Do not donate blood while taking mycophenolate mofetil and for at least 6 weeks after your last dose.

Prednisolone

This is also referred to as 'steroid'. It has other uses but it is prescribed for you as an immunosuppressant to prevent rejection.

You will be supplied 5 mg tablets (not enteric-coated tablets). Enteric-coated (EC) tablets are not recommended due to their unpredictable absorption.

You will be advised the dose on the number of milligrams (not number of tablets).

The transplant clinic may wish to prescribe other strengths for you in the future if a lower dose is needed.

How do I take prednisolone?

- Take once a day, every morning with or after food (breakfast time). Food will
 protect against stomach irritation caused by prednisolone. You will also be
 prescribed lansoprazole to protect your stomach while on prednisolone and/or
 aspirin (to start on discharge where there is no allergy, previous unwanted
 effects or contraindication).
- The dose will be gradually reduced by the transplant clinic as your response to treatment improves. On the other hand, the dose may also be increased if you become unwell.

Steroid card

A blue steroid card is supplied together with the prednisolone tablets from pharmacy. This is a life saving card and you should <u>carry this card in your wallet or purse at all times</u>. The card contains your current dosing information. The prescriber can provide you with a new card should the dose be changed in the clinic. This is important if you fall ill or are involved in an accident. The paramedics may need to give you a steroid injection to save your life.

Report any signs of infection (e.g. cough, sore throat or temperature) to the kidney specialist.

If you are infected with threadworms, or suspected of or come into contact with anyone (including young children) with chickenpox or shingles you should contact the transplant clinic immediately. This is because you may become seriously ill as you are taking a steroid. Additionally, wounds and cuts will not heal as quickly as usual when you are taking a steroid.

Side-effects

Like any medicine (or even food you take), prednisolone may cause some unwanted effects. Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are:

- Increase in appetite and weight gain.
- Mood changes and difficult sleeping, usually with a higher dose.
- Skin changes, your skin may become thinner and you might bruise more easily, acne, increased hair growth on face and body.
- Increase in blood pressure
- Increases risk of developing diabetes.
- Osteoporosis in the longer term.

Always inform any healthcare professional (doctor, dentist, hospital pharmacist, local chemist or nurse) who treats you that you are taking prednisolone, or show them your blue steroid card.

Ciclosporin

Barts Health NHS Trust uses Deximune® brand only.

Deximune® is available in strengths below:

- 25 mg soft capsules
- 50 mg soft capsules
- 100 mg soft capsules

You will be supplied 25 mg, 50 mg and 100 mg soft capsules on discharge. You will be advised the dose on the number of milligrams (not number of capsules).

You must check the strength of the capsules before swallowing the correct dose. For example, any wrong strength (between 25 mg and 100 mg capsules) may result in four times more than the intended dose. There is no antidote in an event of an overdose. Please contact the transplant clinic or ward 9E if after working hours as soon as possible if you have taken the wrong dose.

The capsules should only be removed from their foil wrapping up to 30 minutes before you are ready to take your dose. The capsules have a strong distinct smell. Some people find it more pleasant to remove the capsules from the foil wrapping and leave them for approximately 30 seconds before taking, as this will minimise the smell for when you take the dose.

How do I take ciclosporin?

- Swallow whole with a glass of water. Do not break or chew the soft capsules.
- Take same time each day, 12 hours apart at 10 am and 10 pm consistently. Food has no effect on ciclosporin.
- On transplant clinic days, do not take the morning dose at home but bring some supply with you. Take the dose <u>immediately after the blood test</u>. Do not wait till you get home as this will be too near to your second dose at 10pm. The second dose should be taken at 10 pm as usual.
- No grapefruit (including juice or any grapefruit containing products), Seville orange (often found in some marmalade) and pomelo. They can increase the amount of ciclosporin in your bloodstream unnecessarily and lead to toxicity. Purple grape fruit juice may reduce ciclosporin level.
- Check labels of juices, juice blends, fruit drinks, sodas and marmalades for these ingredients.
- Avoid herbal remedies. Some herbal products e.g. St John's wort (hypericum perforatum) are known to affect the effectiveness of tacrolimus.

Side-effects

Like any medicine (or even food you take), ciclosporin may cause some unwanted effects. Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are;

- Increased blood pressure and cholesterol
- You may become shaky if the level of ciclosporin in your blood is very high.
- Nausea or diarrhoea, if you develop vomiting or diarrhoea that lasts longer than a day please contact the transplant team for advice.
- Swollen gums, regular dental checks are recommended
- It can cause an increase in hair growth

Azathioprine

You will be supplied 25 mg and 50 mg tablets.

You will be advised the dose on the number of milligrams (not number of tablets).

You must check the strength of the tablets before swallowing the correct dose. For example, any wrong strength (between 25 mg and 50 mg tablets) may result in two times more than the intended dose. There is no antidote in an event of an overdose. Please contact the transplant clinic or ward 9E (if after working hours) as soon as possible if you have taken the wrong dose.

How do I take azathioprine?

- Swallow whole with a glass of water.
- Take once a day, every morning with or after food (breakfast time)

Side effects

Like any medicine (or even food you take), azathioprine may cause some unwanted effects. Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are:

- Diarrhoea, nausea, vomiting and headache
- This drug suppresses your bone marrow which mean you may have a lower white cell count, anaemia or lower platelet count which will make you more vulnerable to infection. You will have regular blood tests to monitor for this.

Preventative medicines

When you are started on immunosuppressants, other medicines are also prescribed to protect you from:

Infection

- **Co-trimoxazole** an anti-bacterial to prevent chest infection known as Pneumocystis pneumonia (PCP). Each course is for 3 or 6 months only.
- Valganciclovir an anti-viral to prevent and/or treat Cytomegalovirus (CMV) infection. Each course is for 3 or 6 months only. Your GP will not be prescribing valganciclovir. This is because the dose is adjusted by transplant clinic according to your kidney function. Remember to check that you have sufficient supplies at home as the dose may change as you improve. Request a prescription from the transplant clinic before you run out of supply. CMV infection can lead to kidney rejection.
- Isoniazid an anti-bacterial to prevent tuberculosis (TB) infections. This will be prescribed to you if you have had a previous infection or you are at risk of contracting TB.
- Pyridoxine a vitamin B₆ supplement to protect you against unwanted effects that can be caused by isoniazid eg numbness and tingling of fingers and toes.
 If your isoniazid has been stopped by the kidney specialist, you will no longer need to take pyridoxine.
- Nystatin an anti-fungal to prevent fungal mouth infection. Each course is for 10 days only. The suspension should be used as a mouthwash by swirling in the mouth before swallowing after drinking or eating. By using it after drinking or eating, it stays in your mouth longer to prevent fungal infection.

Heart attack

- Aspirin an antiplatelet to thin the blood so that it flows smoothly, preventing heart attack.
- Atorvastatin a cholesterol lowering tablet to prevent fats from blocking your blood vessels.

Stomach irritation

 Lansoprazole - to prevent stomach irritation (and indigestion) caused by prednisolone and/or aspirin. Immunosuppressants may also cause stomach upset.

Osteoporosis and bone fracture

Adcal D3 chewable tablet – a calcium and vitamin D tablet to chew or crush
(if it is too big to swallow) to protect your bones. It is important that you take
these tablets daily to strengthen your bones. You are at risk of osteoporosis
and bone fracture due to prednisolone, previous malnourishment when unwell
and increasing age.

Dietary information

One of the benefits of a successful kidney transplant is that you can enjoy more variety in your diet.

In some instances however, during the early stages after the transplant operation you may be advised to continue restricting some foods until the kidney is working properly. The transplant team and / or the dietitian will advise you on this when necessary.

Food safety

Following food safety guidance is important for everybody who has had a transplant, but is particularly important when high doses of immunosuppressive medication are recommended or when dose adjustments are made. This is likely to be the case within the first six months after transplantation but this will vary for each patient.

The Food Safety Agency recommend following the **4Cs** of good food hygiene:

- 1. Wash your hands properly and keep them **clean**
- 2. **Cook** food properly
- 3. **Chill** food properly
- 4. Avoid cross-contamination

Please see table 1 for a summary of the food safety guidelines.

Eating Out and Takeaways

Eating out or consuming takeaways within the first 6-8 weeks after transplantation should be avoided.

Medications (immunosuppressants)

Some of the medications may have side-effects that will require dietary changes.

<u>Early side-effects</u> include an increase in the potassium levels and a decrease the phosphate levels in your blood. These occur for a short period after the transplant. Your blood sugar levels may also be unstable. You will be given advice on how to manage this should it be necessary.

<u>Long term side-effects</u> can include weight gain that is common after having a transplant. This could lead to high blood pressure, diabetes and heart disease.

You will be advised by the transplant team when any dietary changes are required.

Foods that interact with medications (immunosuppressants) Important:

The following foods should be avoided:

- Grapefruit and grapefruit juice can increase tacrolimus, ciclosporin, and statins (e.g. atorvastatin, simvastatin)
- Pomelo (shaddock and pampelmousse) can increase tacrolimus and ciclosporin levels

- Seville bitter orange; often used in marmalade may increase tacrolimus and ciclosporin levels
- Star fruit may cause reduction in tacrolimus and ciclosporin levels

It is not recommended to take any 'alternative' medicines such as herbal or homeopathic or high dose vitamins or any non-prescription medicines without first discussing with the transplant team.

Delayed Graft Function

Post transplantation, graft function can vary with periods of reduced urine output and some individuals may require dialysis. During this time certain dietary restrictions may be necessary, including potassium. Food safety is important during this time, as frequent changes to immunosuppressive medication can occur during this time.

Healthy eating

For those with a good functioning graft, producing good volumes of urine, it may be possible to relax these restrictions and start following a healthy diet. To ensure the new kidney stays as healthy as possible it is important to return to a healthy diet low in sugar, fat, salt and high in fibre.

Please note this is a summary of the dietary advice after a transplant. Should you have any queries or wish to be seen by a dietitian please ask any member of the transplant team to refer you or call **0203 594 1101**.

Table 1: Food safety advice for renal transplant patients

High risk - should be avoided	Safer alternative
Unpasteurised milk	Any pasteurised milk, soya milk,
e.g. milk sold on local farms	Jersey milk or UHT milk
All unpasteurised soft cheese unless cooked	Pasteurised soft cheese (check the
until piping hot	label*) for example cottage cheese,
	mozzarella, feta, cream cheese,
Homemade cheeses such as labneh/paneer	ricotta, halloumi, hard goats cheese,
	paneer and labneh.
Dolcelatte	
	Processed cheeses such as cheese
	spreads for example Dairylea
Soft cheeses – mould-ripened (white rind)	All postourised bord shapes such as
brie, camembert and certain goats cheese like chevre	All pasteurised hard cheese such as Cheddar, red Leicester, edam, gouda,
like dievie	stilton, pecorino and parmesan
Blue-veined cheese suchas Danish Blue,	Stittori, peconino ana parmesari
gorgonzola, Roquefort	Mould-ripened cheeses if cooked until
gergeriation, requestors	piping hot
Cheeses on the deli counter	Figure 9
	Blue-veined cheeses if cooked until
	piping hot
	It is best to buy pre-wrapped cheese

	T
Any form of unpasteurised yoghurt	Any yoghurt that does not describe
	itself as 'bio' or 'probiotic' for example
Yoghurt which is described on the label as	live, plain/natural, sour cream, Greek
'bio' or 'probiotic' for example Onken, Yeo	and fruit yoghurts such as Muller,
valley, Rachel's, Activia and others.	supermarket own, lassi and others.
Probiotic drinking yoghurts such as Yakult,	Prebiotic yoghurts / products. These
Actimel, Supermarket own versions	contain substances which promote the
	growth of healthy bacteria. They do not
	contain any live bacteria themselves.
Ice cream from ice cream vans and soft	Shop bought tubs of ice cream stored
serve machines for example whipped ice	and consumed according to
cream	manufacturer's instructions, individual
	ice cream portions
Homemade ice cream using raw eggs	Homemade ice cream using
	pasteurised egg or an egg free recipe
Raw or undercooked meat or poultry	Well cooked meat and poultry
Rotisserie chickens	Tinned meat
Meat or poultry from deli counters	Pre-packaged cooked meats and
	poultry stored and used according to
	the manufacturer's instructions
Cured meats e.g. salami, Parma ham,	
chorizo and pepperoni	Cured meats if cooked until piping hot
Meat and vegetable pâtés	Tinned pâtés
Raw or undercooked eggs	Use lion stamped eggs and cook well
	, 55
Sauces, desserts and dressings made with	Shop bought mayonnaise
raw eggs for example homemade	
mayonnaise, aioli, Caesar salad dressings,	Products made with pasteurised egg
hollandaise and béarnaise sauces, chocolate	
mousse and egg-nog.	
Raw/undercooked fish and shellfish such as	Fish and shellfish if cooked until piping
sashimi, oysters and caviar	hot
Overhi errede with many field /ele ellfield	Tinned fish
Sushi made with raw fish/shellfish	Suphi mode with socked sectored as
Fish and shallfish from onen sounters	Sushi made with cooked seafood or
Fish and shellfish from open counters	vegetables Pre-packaged fish and shellfish stored
	and used according to the
	manufacturer's instructions
Cold smoked fish for example smoked	manarataror o mondonorio
salmon and trout, ready to eat fish and	Consume cold smoked fish/ready to
shellfish unless consumed within 24 hours	eat fish including smoked salmon
	within 24 hours of opening the packet
Unwashed fruits, vegetables and salad	Wash all fruit, vegetables and salad
Unpasteurised fruit juice and smoothies	Pasteurised fruit juice and smoothies
and and an an indication	

Raw sprouted seeds	Thoroughly cook sprouted seeds
Ready to eat sandwiches that contain high risk foods e.g. cured meat or smoked salmon	All other pre-packaged sandwiches which have been stored and consumed according to manufacturer's instructions
Reheated cooked rice and rice dishes	Freshly cooked rice served immediately

Avoid alcohol

Although the current limit is 14 units a week, you should avoid alcohol where possible. If necessary (e.g. festive occasions), always drink less and spread your drinking over the week i.e. having drink-free days each week.

For example, one glass of white wine or a pint of lager is approximately 2-3 units depending on the strength. Please visit www.alcoholconcern.org.uk/unit-calculator for alcohol unit calculator.

Drinking alcohol increases the risk of cancer, this includes regular light drinking. The less alcohol you drink, the lower the risk of cancer. No type of alcohol is any better or worse than another (e.g. wine, beer and spirits). This is because alcohol damages the cells in many parts of the body, including the mouth.

Alcohol may also interact with some of your transplant medicines and/or your medical condition. They include tacrolimus, aspirin, atorvastatin, moxonidine, isoniazid amongst others. This may lead to intolerable side-effects.

Tacrolimus may cause visual and neurological disturbances. This effect may be enhanced if tacrolimus is administered in association with alcohol.

DO

- ✓ Take your medicines AT THE SAME TIME EACH DAY.
- ✓ Store medicines in a cool, dry place, away from pets and children.
- ✓ Ensure you receive the same brand of ciclosporin or tacrolimus every time you collect your prescriptions. Any discrepancies should be clarified with the transplant clinic.
- ✓ Consult a doctor or pharmacist before taking any new medication, including those available over the counter, herbal remedies or vitamin supplements.
- ✓ Seek advice from your doctor or pharmacist if any of the side effects become troublesome, or if you experience side effects not listed in this booklet.
- ✓ Carry your blue steroid card with you at all times.
- ✓ Attend scheduled clinic appointments.
- ✓ Avoid any vaccinations unless discussed with the transplant clinic beforehand.
- ✓ Visit the dentist regularly and maintain good oral hygiene to minimise the risk
 of bleeding gums (whilst taking ciclosporin).
- ✓ Avoid contact with people infected with chicken pox or tuberculosis.
- ✓ Wear appropriate clothing and use sun-block when out in the sun.
- ✓ Report any signs and symptoms suggestive of infection, or diarrhoea/vomiting to the transplant clinic immediately.
- ✓ Follow the dietary information provided about foods to avoid

DON'T

- Share your medication with anyone else, even if their symptoms appear to be similar to yours.
- × Run out of medication or MISS any doses.
- Never double up on medication to make up for missed doses.
- * Take tacrolimus OR ciclosporin on clinic days BEFORE a blood test.
- **x** Stop treatment unless instructed by the transplant clinic.
- Buy over-the-counter non-steroidal anti-inflammatory drugs such as ibuprofen (eg Nurofen®) or diclofenac (eg Voltarol®).
- **×** Go out in the sun too much without protecting your skin.
- ★ Use sun-beds or have light treatment (PUVA or other UV treatments).
- No sun bathing!

Glossary of blood tests

Term	Normal Range	Explanation
Hb (haemoglobin)	Male 135-175 g/L Female 120-160 g/L	Haemoglobin is the oxygen-carrying protein inside red blood cells; low levels may indicate you are anaemic.
WBC (white blood cells)	4-11x10^9/I	White blood cells are important in fighting infections. The count can rise as a result of infection or from taking steroids. A low count can indicate that the medication is affecting your bone marrow.
Platelets	150-400x10^9/I	Platelets are essential for normal blood clotting. A low count may indicate that your medication is affecting the bone marrow.
Neutrophils	2-7.5x10^9/l	Neutrophils are a type of white blood cell that usually rises to fight infection. A low level may indicate the medication is affecting your bone marrow.
Creatinine	Individual basis	The creatinine test indicates how well your transplant kidney is working.
CRP	0-5mg/l	The CRP marker is an indicator of inflammation which may be raised due to active disease or infection.
LFTs (liver function tests)	Individual basis	The liver function group of tests includes ALT, AST, AlkPhos, Bilirubin. These tests are performed to check liver function. A rise in some of these levels can indicate inflammation of the liver. This is sometimes caused by your immunosuppressant medication.



Patient Advice and Liaison Service (PALS)

Please contact us if you need general information or advice about Trust services. www.bartshealth.nhs.uk/pals

Large print and other languages

For this leaflet in large print, please speak to your clinical team. For help interpreting this leaflet in other languages, please ring 020 8223 8934.

Te informacje mogą zostać na żądanie przedstawione w formatach alternatywnych, takich jak łatwy do czytania lub dużą czcionką, i w różnych językach. Prosimy o kontakt pod numerem 02082238934.

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Bu bilgiler, okuması kolay veya büyük baskılar gibi alternatif biçimlerde ve talep üzerine alternatif dillerde de sunulabilir. İrtibat için lütfen 02082238934 numaralı telefondan ulaşın.

اس معلومات کو متبادل شکل، جیسے، پڑ ہنے میں آسان یا بڑے حروف، میں دستیاب کر ایا جا سکتا ہے، اور درخواست کرنے پر اسے متبادل زبان میں بھی دستیاب کر ایا جا سکتا ہے۔ بر اہ مہربانی 02082238934 پر رابطہ کریں۔

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All our patient information leaflets are reviewed every three years.

