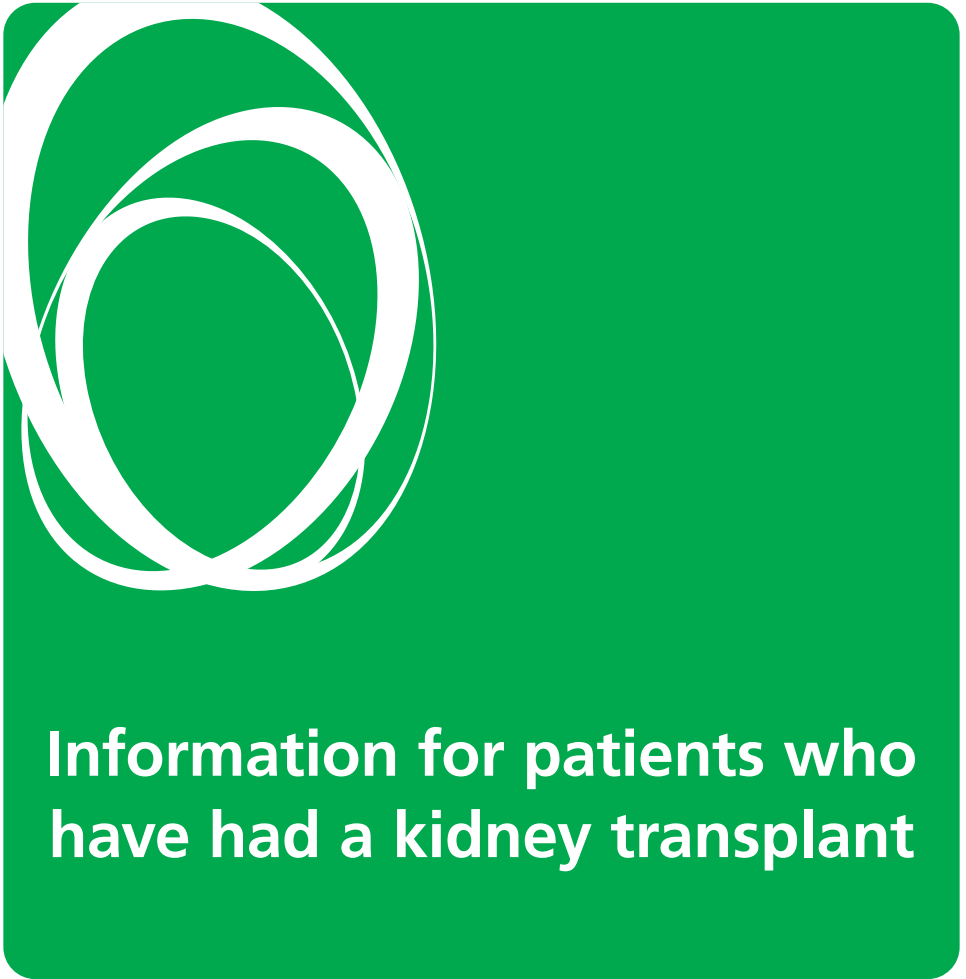




**University Hospitals Birmingham**  
NHS Foundation Trust



**Information for patients who  
have had a kidney transplant**

**Building healthier lives**

**UHB is a no smoking Trust**

## Introduction

This booklet has been written for patients who have received a kidney transplant at Queen Elizabeth Hospital Birmingham. It provides information about the kidney transplant operation and the recovery period. The aim is to help you and your family/carer become more aware of what to do to keep yourself and your transplanted kidney in good health, and also what to do if you think you have a problem.

Below is a list of useful contact numbers for the Queen Elizabeth Hospital Kidney Transplant Team:

08:00–18:00 Monday to Friday: Kidney Transplant Coordinators – **0121 371 4433**.

18:00–08:00 and weekends for urgent telephone advice only: Call the hospital Switchboard on **0121 371 2000** and ask to speak to the renal transplant doctor on-call.

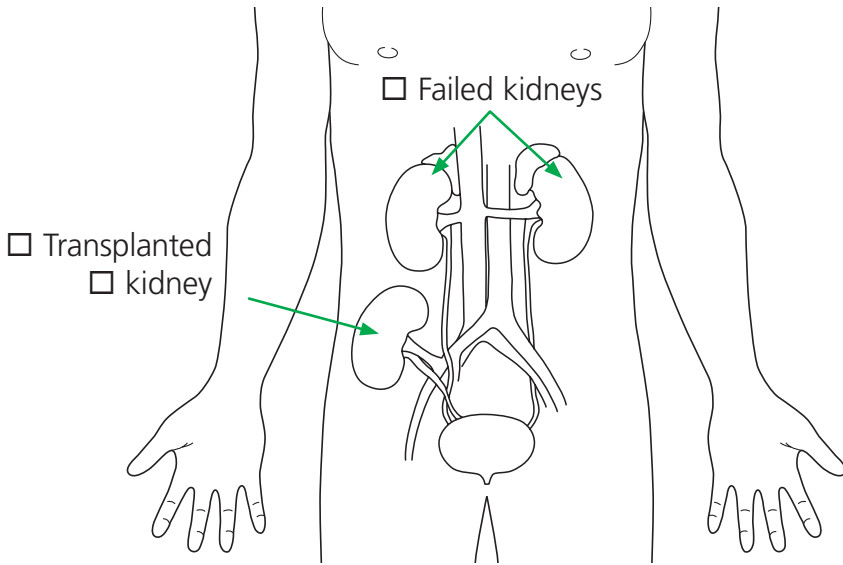
Outpatient clinic enquiries: Renal Transplant Clinic, Area 2 (Office hours) – **0121 371 5630**.

Renal Assessment Unit on level 3 (RAU): **0121 371 4446**.

Post transplant advanced nurse practitioners: **0121 371 4446**.

# The kidney transplant operation

The operation takes about two to four hours. The transplanted kidney is usually placed in either the right or left groin area, as illustrated. It is placed here as it is close to your bladder. Normally your own kidneys are not removed unless there is a reason to do so. As a result, you will end up with three kidneys (your own 'native' kidneys and the transplanted one). The operation requires the surgeon to join up your blood vessels to those of the transplanted kidney. The urine tube (ureter) that will drain the urine from the transplanted kidney will be connected to your bladder.



## After the operation

After the kidney transplant has been carried out you will usually return to the renal ward (Ward 303). Sometimes it may be necessary for you to be looked after in the intensive care unit for a day or two, depending on your recovery from the operation. The nursing staff will make sure that you are comfortable and will monitor your transplanted kidney to make sure it is working well.

### **When you wake up you will notice that you have a number of different plastic tubes in your body, the most common ones are:**

- A tube in your neck to help us to give you fluids and give you temporary dialysis if required
- A small tube in your hand or arm to give you medications and pain relief. You will be given a pain control device (PCA or patient controlled analgesia). This is a hand held device with which you can deliver a dose of painkillers yourself as required
- A plastic drain tube in your abdomen to help drain away any blood and fluid from the operation
- A urinary catheter, a tube which passes up your urethra into the bladder, to help us monitor your urine output
- Most of these tubes should be removed after 2–3 days. The urinary catheter will remain for 5 days to allow the sutures to heal
- Sometimes the transplant surgeon uses a small plastic tube during the transplant operation (ureteric stent). This is placed between your transplanted kidney and your bladder to help maintain the flow of urine. The stent will be removed after 6 weeks as a day case procedure using a local anaesthetic

## Recovering from the operation

Eating and drinking is usually encouraged as little as 6 hours after the operation. Whilst you are in hospital, your transplant nurse will encourage you to record everything you drink and measure the urine you pass, even after your urinary catheter has been removed. This will help us to check how well your transplanted kidney is working.

On the first day after your operation, your nurses or physiotherapist will help you out to your chair for a few hours where you will be taught how to carry out deep breathing exercises. You will be encouraged to be mobile around the ward as soon as possible as this will help speed up your recovery and reduce your chances of getting a chest infection or a blood clot in the leg. You are likely to be in hospital for 6-10 days following a kidney transplant. However this could be longer depending on your condition and your recovery.

### **There are different ways used to close the wound after your transplant operation:**

- **Staples:** these will be removed in clinic 2–3 weeks after your operation
- **Glue:** this will eventually dissolve. For the first few weeks, try and keep the wound area as dry as possible when showering and avoid baths

One of the transplant clinic nurses will look at your wound when you come to your clinic appointment to ensure that it is healing.

### **Following discharge you will be seen in the outpatient clinic very regularly, twice a week to start with.**

## **Complications associated with kidney transplantation**

Although kidney transplantation is a very successful treatment for kidney failure, complications can occur. Your transplant team will do their best to reduce your chance of having any complications and to treat any arising problems straight away. You can minimise the risk of complications by following the advice we give to you carefully and keeping your transplant team informed of any problems that occur.

**Problems associated with kidney transplantation:** A **thrombosis** (blood clot) can form after the operation and blocks one of the blood vessels. This would require a further operation to rectify the problem.

Sometimes a leak between the kidney drainage tube (ureter) and the bladder (**urinary leak**). You may need a small operation to insert a catheter or drain temporarily to resolve the problem.

A collection of fluid (called a **lymphocele**) may collect around the kidney transplant. This may need to be drained.

About half of all transplanted kidneys will not work immediately; this is called **delayed graft function**. It may take several days for your transplanted kidney to start working and you may need dialysis during this time. If your kidney takes more than a few days to start working properly, or temporarily stops, your doctors may take a tissue sample (biopsy) of the transplanted kidney to see if your body is rejecting it.

**Failing to drink enough may lead to dehydration** which can damage your transplanted kidney. You might find it difficult to drink plenty of fluid after your kidney transplant, especially if you had previously been restricting your fluid intake. To help prevent complications associated with dehydration you should aim to drink between 2–3 litres of fluids a day unless we have told you otherwise. If you start to develop diarrhoea and vomiting, it is essential to increase your fluid intake to prevent yourself from becoming dehydrated. If you are unable to keep your fluids and transplant medications down then you should contact your transplant team for advice.

**High blood pressure** is very common following a kidney transplant, particularly during the early months. After a kidney transplant many people require blood pressure lowering medication. It is vital to control high blood pressure as, if left untreated, you could be at risk of heart disease or a stroke and it can damage your transplanted kidney.

**Rejection** can occur after a kidney transplant. Roughly 30 in 100 patients will experience acute rejection within the first 6 months of their transplant. Your body will recognise that your transplanted kidney is 'foreign' and the natural response is to attack and reject it. You will

have been given anti-rejection medication to reduce the chance of this happening; these medications will need to be taken for the life of your kidney transplant.

Rejection is treated by changing the dose of your anti-rejection medication and/or by prescribing a new medication in addition. As rejection can be detected following one of your regular blood tests it is critical that you attend your clinic appointments regularly. Rejection does not necessarily mean loss of your transplanted kidney.

**The signs of rejection can include:**

- Pain or tenderness over your transplanted kidney
- Fever
- Fatigue/weakness
- Reduced urine output
- Flu-like symptoms
- Sudden weight gain
- Swelling in hands or feet
- A rise in blood pressure

Some patients will experience **anxiety and mood swings** as the transplant operation can put a lot of stress on you and your family. It is very common for patients or relatives to have anxieties. There are counselling services to help you adjust to life at home. Please ask your transplant team for more information about these services.

The anti-rejection medication will make you more likely to develop **infections**. The risk is greater in the early stages after your transplant because the doses of your anti-rejection medication will be higher. It is important that you inform your transplant team if you think you have an infection. If you know family or friends who have a serious infection it is a good idea if you avoid visiting them while they are unwell.

The majority of infections for example wound, urinary and chest infections are caused by common bacteria, which can be treated with

antibiotics. However, because of your anti-rejection medications you are also at risk of other infections that can usually be prevented or treated. With time the increased risk of infection lessens but never goes away completely. The following are some of the most common infections:

**Fungal infections:** Thrush – this is caused by a fungus called candida. It can infect your wound, mouth, eyes, respiratory and urinary tract. In the mouth, thrush can cause soreness, a white film on the tongue and difficulty in swallowing. It can also infect the oesophagus or gullet (the tube from your mouth to the stomach). In women, thrush can also infect the vagina, causing an abnormal discharge and itching. Severe fungal infections may require you to come into hospital for treatment.

**Viral infections:** Three quarters of the UK population have had cytomegalovirus (CMV); the symptoms are similar to a cold or flu. If you have not had a CMV infection prior to your transplant then it can be passed on to you through the transplanted kidney. If you have had the virus in the past it can become reactivated after your transplant. In order to prevent a CMV infection, we give you tablets (valganciclovir) for the first few months after your transplant, when you are most at risk of developing a CMV infection. As CMV can still occur once these tablets have been stopped, we regularly test for it in your blood when you come to clinic. Signs of CMV infection include fatigue, fever, sweating (especially at night), aching joints and headaches. If you are unwell with CMV, you may need to be admitted to hospital for treatment.

Most adults have had a **BK virus** infection without knowing it. Following your transplant, BK virus can reactivate. This will not make you feel unwell but it can damage your transplanted kidney. Treatment of BK virus involves reducing your anti-rejection medication in order to allow your body's immune system to clear the virus. We regularly test for the virus in your blood when you come to clinic and occasionally we will need to take a biopsy (tissue sample) of your transplanted kidney to make sure that the virus is not causing inflammation.



**Cold sores** [herpes-simplex virus (HSV) types 1 and 2] generally infect the skin around the mouth causing painful blisters. They can also turn up in other areas of your body including the eyes, lungs and genitals. Herpes can be treated, but not cured, by using creams and medication available from your GP or local pharmacist.

**Shingles** (herpes zoster) appears as a rash or small blisters usually on the side of the face, chest, abdomen or back. The rash may not be painful and only occurs in people who have had chicken pox in the past. Call your GP or transplant team immediately if you think you have shingles as you will need treatment.

**Chicken pox** (varicella) may appear as a rash or small blisters. Chicken pox usually occurs in childhood. If you have been exposed to someone with chicken pox or shingles and you do not think you have had chicken pox previously, please contact your GP or transplant team immediately. Do not wait to see if you are going to be sick.

**Other infections:** Pneumocystis is a germ that is normally found in the lung. After your transplant you will be given tablets (co-trimoxazole) to prevent you from catching this. Symptoms can include breathlessness and a cold or flu that does not go away.

**It is important that you contact your transplant team if you think you have any of the above infections.**

## Going home

### **Below is a checklist of items you need to take home with you:**

- A supply of your prescribed medication. This will be arranged by the transplant ward team before you leave
- A list of your medication including their names, doses and how often they should be taken
- A copy of your discharge letter
- A clinic appointment (ensure you have transport booked if required)
- A white topped urine specimen bottle to bring a urine sample to your next appointment
- Wound dressings for the first dressing change by your practice/ district nurse or for you to change yourself

## When you get home

Once you have been discharged home it is important that you are aware when you should seek medical advice.

### **You should contact your transplant team or the ward for urgent medical advice if you think you have suddenly developed one of the following in the first few weeks after your transplant:**

- Abdominal pain that is not controlled by your pain relief
- Reduced urine output
- Blood in your urine
- Bleeding
- Fevers or a raised temperature of 38°C or above
- Diarrhoea and/or vomiting for more than 24 hours
- Chest pain
- Difficulty breathing
- Swelling in the face, stomach or legs

If you are unsure and cannot get over the phone advice, please phone NHS Emergency and Urgent Care Services on **111** or attend your local accident and emergency department.

## Clinic arrangements

Following discharge from hospital you need to attend regular transplant clinics in the Outpatients Department at the Queen Elizabeth Hospital Birmingham. For the first few weeks it is very important that we see you twice a week to make sure both you and your transplanted kidney are doing well. Over time these clinic appointments will become less frequent. Before you leave hospital the ward will make your first clinic appointment for you. If you would like to have access to your blood results via the hospitals IT system please ask a member of the transplant team and this can be set up for you.

### **When attending clinics please remember:**

- Do not take your morning dose of Adoport (tacrolimus), Neoral (ciclosporin) or Sirolimus on your clinic days until you have had your blood test. Ensure that you bring the dose with you to clinic so that you don't miss it
- Bring an up-to-date list of your medications with you
- Make sure you have your next clinic appointment before you leave

If you are unable to attend the clinic for any reason, please inform the clinic team using the contact information at the front of this booklet.

If you were referred from a kidney unit other than the Queen Elizabeth Hospital Birmingham (such as New Cross, Russel Halls, Birmingham Heartlands Hospital, Royal Shrewsbury Hospital) you will normally be referred back to your kidney centre approximately 3 months after your transplant operation. If you were referred from the Royal Stoke Hospital team you will be referred back to the Stoke kidney team on discharge. We will ensure they are aware of your kidney transplant operation and ensure you have an appointment with them before leaving the Queen Elizabeth Hospital Birmingham.

We encourage you to arrange your own transport to and from clinic as strict rules apply to determine whether hospital transport can be provided for you. However if you have any concerns please discuss with your transplant team.

## Medications after transplant

Before you are discharged from hospital the transplant coordinator team will go through your new medicines with you giving you information on what to take, when to take it and why you need to take it. You will need to take these new medicines called anti-rejection or immunosuppression for the life of the kidney transplant.

It is very important that you do not forget to take a dose. If you have forgotten to take a dose, continue to take your medicines as normal. Do not take twice the usual amount. Let your transplant team know if you miss a dose. If you have been sick or have been having diarrhoea within 2 hours of taking your medication, the medicines may not work. Please call your transplant team for advice. It is important that you do not stop or change your medicines unless you have been told to do so by the transplant team.

Ideally you should avoid using non-prescribed medication, such as recreational drugs, herbal medicines or remedies, diet and beauty pills/medicines, and body building drugs. These types of medicines have been known to cause irreversible kidney damage.

When you leave hospital you will be given a 14 day supply of medicines together with a medication card detailing what you need to take and when. Remember to bring your medication card with you when you visit for appointments. You will get certain transplant medicine supplies from the hospital pharmacy and others from your GP. If you have any problems getting any medicines, please do not hesitate to contact us.

**You must not be without your transplant medicines.**

## **Tacrolimus (Adoport® or Advagraf®)**

### **What is tacrolimus?**

Tacrolimus is one of the medicines used to stop the body attacking transplanted kidneys.

It is available as two different formulations, Adoport® or Advagraf®. Adoport® is taken twice daily and is available in 0.5mg (white and ivory), 1mg (white and light brown) or 5mg (white and orange) capsules. Advagraf® is only taken once a day and is available in 0.5mg, 1mg, 3mg or 5mg capsules. There are other brands of tacrolimus available (e.g. Prograf). It is very important that you remain on the same brand recommended and prescribed by the hospital.

### **How should I take it**

Swallow the capsules whole (without chewing) with a glass of water either consistently on an empty stomach or consistently with food. If you choose to take this on an empty stomach, please ensure that it is taken either 1 hour before or 2–3 hours after food (this is because fatty foods can slow the absorption of tacrolimus).

### **Do not take any grapefruit products (including juice).**

Adoport® is taken twice a day. On clinic days, it is important that we obtain a blood level 12 hours after your last dose. You will need to take your medication 12 hours before your blood test is due. Therefore if your appointment is at 10:00, take your medicine at 22:00 the night before. Please do not take your tacrolimus (Adoport®) on the morning of your clinic appointment. You will need to bring the tacrolimus (Adoport®) medication with you to the hospital so that once you have had your blood test done you can then take your medication. It is common for your dose to be changed after the result of the blood test has been checked. The doctor or clinic nurse will call you after clinic to

ask you to change your dose. Always make sure you know what dose to take and keep your record card updated.

### **Can I take other medicines with tacrolimus?**

Many other medicines can increase or decrease the level of tacrolimus in your blood. This includes conventional medicines e.g. some antibiotics and alternative medications e.g. St. Johns Wort. These can either increase the risk of side-effects or allow your body to attack the transplanted kidney.

Check with your doctor or pharmacist before taking any new medicines or supplements including those bought over the counter. Always buy any medicines or remedies from the pharmacy after showing your medication card to the pharmacist.

### **Are there any side-effects?**

Tacrolimus has some side-effects but not everyone will experience these. If you have a side-effect then tell the nurse or doctor as there may be a simple solution. Side-effects can include:

- Tremor (shaking) in the hands
- Headaches
- Visual disturbance (blurred vision)
- Changes to blood sugar levels and blood pressure
- Problems with sleep
- Increased risk of infections
- Increased cholesterol levels
- Certain cancers including skin cancer
- Hair loss

If the dose is too high, it can make your kidney work less efficiently. Blood tests will usually pick this up very quickly and your doctors will adjust the dose to put this right.

# Ciclosporin

## What is ciclosporin?

Ciclosporin is one of the medicines used to stop the body attacking transplanted kidneys. It is available in different formulations, Neoral®, Sandimmun® and Deximune®. All brands are available as capsules of 25mg, 50mg and 100mg and Neoral® is also available as a liquid of 100mg in 1ml (which is measured using an oral syringe).

Once you have started taking one formulation (normally Neoral®), do not swap to the other unless your hospital doctor tells you to.

## How should I take it?

Swallow the capsules whole (without chewing) with a glass of water. Read the leaflet which comes with the liquid carefully before taking.

## Do not take any grapefruit products (including juice).

Neoral® is taken twice a day. On clinic days, it is important that we obtain a blood level 12 hours after your last dose. You will need to take your medication 12 hours before your blood test is due. Therefore if your appointment is at 10:00, take your medicine at 22:00 the night before. Please do not take your ciclosporin (Neoral®) on the morning of your clinic appointment. You will need to bring the ciclosporin (Neoral®) medication with you to the hospital so that once you have had your blood test done you can then take your medication. It is common for your dose to be changed after the result of the blood test has been checked. The doctor or clinic nurse will call you after clinic to ask you to change your dose. Always make sure you know what dose to take and keep your record card updated.

## Can I take other medicines with ciclosporin?

Many other medicines can increase or decrease the level of ciclosporin in your blood. This includes conventional medicines e.g. some antibiotics and alternative medications e.g. St. Johns Wort. These can

either increase the risk of side-effects or allow your body to attack the transplanted kidney.

Check with your doctor or pharmacist before taking any new medicines or supplements including those bought over the counter. Always buy any medicines or remedies from the pharmacy after showing your medication card to the pharmacist.

### **Are there any side effects?**

Ciclosporin has some side-effects but not everyone will experience these. If you have a side-effect then tell the nurse or doctor as there may be a simple solution. Side-effects can include:

- Tremor (shaking) in the hands
- Headaches
- Swollen, tender gums
- Changes to blood sugar levels and blood pressure
- Numb, hot or tingly hands, feet or mouth
- Increased risk of infections
- Increased cholesterol levels
- Certain cancers including skin cancer
- Increased hair growth on the body, legs and face

If the dose is too high, it can make your kidney work less efficiently. Blood tests will usually pick this up very quickly and your doctors will adjust the dose to put this right.

## **Steroids (e.g.Prednisolone)**

### **What is Prednisolone?**

Prednisolone is a steroid. It is similar to the ones produced by naturally the body and prevents the immune system attacking the kidney. After one week or so of taking Prednisolone, your body will gradually stop making its own steroid. If you then stop taking prednisolone suddenly, your body will not have enough steroids and this can be very serious. For this reason any dose reductions will be small and gradual. You



will be given a blue 'steroid treatment card', with your details on. This will alert anyone who treats you that they need to keep giving you steroids. Carry this card with you all the time.

Uncoated Prednisolone is available as 1mg, and 5mg tablets. You must not take the red, coated tablets. Take the tablets with or just after breakfast and tea is recommended as this helps prevent indigestion. It is normally recommended that you do not take the evening dose any later than 17:00, otherwise you may not be able to sleep properly at night.

### **Are there any side effects?**

Steroids have a number of possible side effects. Most happen slowly over a period of time and are worse if the dose is high. For this reason the doctors will always reduce the dose to the smallest amount which prevents your body attacking the kidney. The following side effects have been noticed in some patients:

- Stomach ulcers and indigestion
- Fluid retention, usually in the form of swollen ankles
- Increased appetite
- Weight gain
- Your face may become more rounded
- Skin changes – you will be more likely to get acne
- Cuts and bruises may happen more easily and be slower to heal
- Osteoporosis (weak bones) may happen over a long period of time making fractures more likely – ask about calcium supplements
- Mood swings
- Increased blood sugars – tell your doctor if you get more thirsty, pass increasing amounts of urine or feel very tired. If you are already diabetic then your blood sugar treatment may require adjusting.
- Increased risk of infections

If these side effects are a problem, tell your doctor. Also tell your doctor if you have any other side-effects.

# Mycophenolate

## What is mycophenolate?

This medicine reduces the number of white blood cells which may attack the kidney and is used in combination with other medicines. It is available as a 250mg capsule and 500mg tablet. There are many different brands available. There is no problem in taking different brands of mycophenolate and as a result you may find the boxes and contents look different each time you collect this medication from the hospital pharmacy.

Swallow the tablets and/or capsules whole (without chewing) with a glass of water and take with food.

## Can I take other medicines with mycophenolate?

Some other medicines can interfere with mycophenolate. These include medicines you can buy without a prescription (e.g. indigestion remedies). Always check with your doctor or pharmacist before taking any new medicines or supplements.

## Are there any side-effects?

Mycophenolate has some side-effects but not everyone will experience these. If you have a side-effect then tell the nurse or doctor as there may be a simple solution. Side-effects can include:

- Feeling sick
- Diarrhoea
- Most common is increased risk of infections

Your doctor will routinely measure your blood counts and will tell you if your dose needs changing. You can take this medication with meals if experiencing stomach upsets. Report signs of infection or unexplained bleeding or bruising to the nurse or doctor. You should not be taking this drug if you are planning a pregnancy. Please discuss with your transplant nurse or doctor.

# Azathioprine

## What is azathioprine?

This medicine reduces the number of white blood cells which may attack the kidney and is used in combination with other medicines. It is available as 25mg and 50mg tablets. There are many different brands available. There is no problem in taking different brands of azathioprine and as a result you may find the boxes and contents look different each time you collect this medication from the hospital pharmacy.

Swallow the tablets whole (without chewing) with a glass of water. It is usual to take this medicine once daily after a meal (to reduce the chance of stomach upset).

## Can I take other medicines with azathioprine?

You should avoid taking allopurinol, which is a medicine used to prevent gout, if you are taking azathioprine. The azathioprine can affect the allopurinol.

## Are there any side-effects?

Azathioprine has some side effects but not everyone will experience these. If you have a side effect then tell the nurse or doctor as there may be a simple solution. Side-effects can include:

- Most common is increased risk of infections
- Rash
- Joint and muscular pain

Your doctor will routinely measure your blood counts and will tell you if your dose needs changing. Report signs of infection or unexplained bleeding or bruising to the nurse or doctor.

## Other medicines you may be asked to take

**You may also be asked to take all or some of the following:**

**Co-trimoxazole** – an antibiotic taken every other day to prevent you developing a certain bacterial chest infection. You will be on this tablet for 6–12 months.

**Nystatin** – an anti-fungal liquid to prevent oral thrush. You will take this liquid for around 3 months.

**Ranitidine or lansoprazole** – indigestion medicines to prevent your stomach from producing too much acid. You will take one of these for around 3 months.

**Valganciclovir** – an anti-viral medication, (this is only needed in some patients) to prevent you from developing active viral infections. You will take this tablet for 100 days.

**Fluvastatin** – this should be started 3 months after your transplant to lower cholesterol levels in your body. It is the only cholesterol lowering medicine that has been tested with kidney transplant patients, and we know does not interact with any of your anti-rejection medication.

**Calcium and Vitamin D3** – this is a calcium supplement that you may have taken previously as a phosphate binder. However you do not take it with food it should be taken on its own as a supplement to help your bones.

**Alfacalcidol or bisphosphonate** – to provide additional protection for your bones.

**Isoniazid** – an antibiotic to prevent you developing TB. This will only be given to you if you are at high risk of developing TB. You will be on this tablet for 6–12 months.

**Pyridoxine** – a vitamin B supplement to prevent you from experiencing tingling in your hands, which can happen with isoniazid. You will only take this whilst you are taking isoniazid (6–12 months).

You may still need to take some medication to lower your blood pressure – your transplant nurse or doctor will advise you on this. Good blood pressure control is vital to maintain good function of your transplanted kidney.

### **Do I have to pay for my medicines?**

Yes, unless you have a special reason or medical exemption certificate. To check whether or not you fall into this category see leaflet HC11 or call **0300 330 1341**. If you have to pay for your prescriptions than a pre-payment certificate may be cheaper for you. For further details you can call **0300 330 1347**.

For more information, speak to the transplant nurse, doctor or pharmacist. Also, you can go to:

**[www.nhsbsa.nhs.uk/help-nhs-prescription-costs](http://www.nhsbsa.nhs.uk/help-nhs-prescription-costs)**

## **Your health after a kidney transplant**

Feel fit and enjoy life! Before your transplant you may have felt too weak and tried to exercise. Many transplant patients find that after they have recovered from the surgery, they have more energy and are eager to increase their level of activity. Once you have been discharged from hospital we encourage you to gradually increase the amount of exercise you take without allowing yourself to become too tired.

### **To avoid developing potential complications please follow the following advice carefully:**

- Avoid lifting heavy weights for at least 6 weeks, gradually increasing the weight you can carry
- Avoid repetitive tasks such as vacuuming or mowing the lawn for the first six weeks
- Avoid the temptation to become stooped over your wound,

- worsening your posture and increasing the risk of back pain
- Gradually improve your exercise tolerance in order to avoid the complications associated with poor levels of fitness
  - Extreme athletic exercise should be avoided for twelve weeks.
  - The only sports to avoid are those where you might get a direct blow to the kidney, for example rugby, boxing or martial arts.
- Although your ability to exercise will depend on you as an individual, regular exercise is important for your general health and wellbeing

### **Incorporating 30 minutes of physical activity in your daily routine will:**

- Lower your risk of developing diabetes following a transplant
- Help to keep your weight down
- Help prevent other health problems, such as high blood pressure and heart disease

Exercise classes and gym membership can provide a structured environment to exercise, however daily activity does not need to be expensive.

### **Consider simple things that you can do every day:**

- Try parking further away from work or other destinations to increase the distance you need to walk
- Cycle to work, rather than drive
- Climb the stairs instead of taking the lift

## **Driving**

We recommend that you do not drive for at least 6 weeks following your transplant. You may wish to check with your insurance company about this.

## **Returning to work**

As a guide, you should anticipate being off work for at least 8 weeks, but this will depend on how you are doing and the job that you do. When you feel you are ready to return to work please speak with one of the transplant team for advice.

## Stop smoking

Smoking is harmful to your health and will reduce the life of your transplanted kidney. Smoking will also increase your chances of developing cancers and chest infections because of the anti-rejection medication you will be taking. We strongly advise that you give up smoking as soon as you can. More advice on stopping smoking can be provided by your GP.

## Your skin

Due to your medication, you are more at risk of skin cancer. Make sure you cover up, wear a hat and use a sun screen that blocks both UVA and UVB rays (factor 30 or more). You should also do this on cloudy days as sun rays still damage the skin. You can still enjoy the sun shine but be sensible and avoid the midday sun. Avoid sunbeds.

You should examine your skin regularly looking for any changes to existing moles and freckles. If you are concerned that your skin has changed please speak to the transplant team. There is a regular skin clinic held in the transplant clinic, where you can see a skin specialist.

If you are having problems with dry skin, use a mild soap and put on a body lotion after showering. If you have cuts or scratches ensure that you clean them. For larger cuts contact your GP. If you discover any unusual skin growth, rash or discoloration, contact your GP.

Tattoos and piercings bring a risk of viral and bacterial infections. We advise you to wait 6 months after your transplant before getting a new tattoo or piercing and to only use a licensed studio.

Some of the medicines you are taking may cause you to grow more hair on your body or may cause hair loss. This is a normal reaction. Please speak to the transplant team for advice if needed. As we reduce your medicine doses, there should be fewer problems with this.

Some people worry about the scar. Your scar will fade over time as your body heals. Don't forget to put sun cream on your scar if it is exposed to the sun.

## Dental care

Make sure that your dentist knows that you have had a kidney transplant and what medication you are taking. It is advisable to have routine dental checks every 6 months and maintain good dental hygiene. Non-healing mouth ulcers could be a sign of oral cancer and should be investigated by your GP.

## Eye care

You should wait until your medications have been reduced before purchasing new glasses/contact lenses (usually about 6 months after your transplant), as your vision can alter in the first few months. It is important to have an eye test (at least every 2 years), to ensure early detection of any eye problems.

## Sexual activity

You can resume sexual activity as soon as you feel well enough to as it will not harm your transplanted kidney. Sexual functioning can be affected by dialysis, transplantation and some medications. If you have any concerns, please feel free to discuss them with one of the transplant team. If you are sexually active and do not have a steady sexual partner, you should use condoms to reduce the risk of sexually transmitted diseases. You should also use contraception to avoid an unplanned pregnancy.

## Pregnancy

With a well functioning transplanted kidney the chance of a successful pregnancy is high. However, if you are planning to become pregnant ask to be referred to the special pre-pregnancy counselling clinic. We advise against pregnancy during the first year after your transplant. If you want a baby then wait at least a year. Having a baby may put a strain on your kidney and there may be drugs that could affect the



baby. Women can become fertile again before their periods return therefore we would recommend that you use contraception to prevent pregnancy.

It is a good idea to ask your doctor or nurse to make sure there are no problems before trying to start a family. In the pre-pregnancy counselling clinic you can be seen and have advice on all changes that need to be made to medication before you get pregnant.

## Contraception

You want your choice of contraception to be safe and secure. Most forms of contraception are safe to use after a transplant.

The combined pill is safe for most women, but it may increase your blood pressure. This should be monitored very carefully and this type of contraception should be avoided if you have a past history of blood clots (thrombosis).

The progesterone only mini pill is safe and effective. Your drug levels must be monitored after starting either types of the pill and you will need to make an appointment for a blood test two weeks after starting the pill. Remember to seek advice if you miss any type of pill. The Mirena intrauterine device (coil) is safe and effective; however you may prefer to have an implant or a contraceptive (Depo-Provera) injection.

Condoms are safe and protect you from sexually transmitted diseases but are not always reliable, so should ideally be used in addition to another method of contraception.

## Advice for women

Due to the medication you are taking it is recommended that you have yearly smear tests; this should be done at your GP surgery.

It is important that you carry out regular self breast examination. This should be carried out monthly at a different time to your period. You

are checking for swelling, lumps, and discharge from your nipple, and remember to check under your arms as well. If you are sexually active you should also be using condoms to protect yourself against sexually transmitted diseases.

## Advice for men

Due to the medication you are taking it is recommended that you that you examine yourselves for any swelling or lumps in your testicles. If you are sexually active you should also be using condoms to protect yourself against sexually transmitted diseases.

If you discover anything you are worried about please consult your GP, or transplant clinic.

## Going on holiday

If you are planning on travelling abroad it is essential that you follow our advice to minimise the risk to yourself and your transplanted kidney. However we do not recommend that you travel abroad for at least 8–12 months after your operation. Before booking an overseas holiday, always check that you are fit to travel with the transplant team.

The transplant clinic will provide you with a letter for customs to cover your medication. Obtaining supplies of your transplant medication whilst away from home can be very difficult or very expensive. You should always take more supplies than you will need for the trip; ensuring that you spread your supplies evenly between hand luggage and your suitcase in case one gets lost or stolen.

Your anti-rejection medication will make you more prone to picking up infections while abroad.

## **You can reduce the risk of getting these infections by following simple advice such as:**

- Avoiding drinking tap water
- Increasing your daily fluid intake
- Ensuring the food that you eat is cooked properly
- Avoiding salads and other raw fruits and vegetables that have been washed in tap water
- Avoiding swimming in areas, such as rivers or seas, that do not have their water quality checked regularly or are known to have waterborne diseases/ parasites
- When planning a trip abroad you need to check well in advance which vaccinations are required, as you should not receive live vaccines whilst taking anti-rejection medication
- You should speak to the transplant team if you are planning to travel to an area affected by malaria as some anti-malarial treatments can affect the levels of anti-rejection medication in your blood. When travelling to areas that are affected by malaria, you should try and minimise the risk of being bitten as contracting malaria whilst on anti-rejection medication can be very dangerous

The list below outlines some of the vaccines you can and can't have. For vaccines not covered below please speak to the transplant team before getting them.

### **Vaccines that are SAFE to have:**

- Flu vaccine
- Inactivated poliomyelitis vaccine (Salk type)
- Pneumococcal vaccine
- Tetanus toxoid vaccine
- Polysaccharide typhoid vaccine (Typhum Vi)

### **Vaccines you should NOT have:**

- MMR vaccine
- Poliomyelitis vaccine live – oral (Sabin type)
- Oral typhoid vaccine (vivotif)

- BCG for tuberculosis
- Smallpox vaccine
- Yellow fever vaccine
- Shingles vaccine – Zostavax

## Insurance

It is very important to get adequate travel insurance before travelling abroad. You should ensure your insurer has full details of your condition. For European travel you need a European Health Insurance Card, which is available free online via the NHS website:

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

If you are finding it difficult to obtain travel insurance, please check with the Kidney Patients Association for recommended companies or visit: **[www.kidney.org.uk](http://www.kidney.org.uk)**

## Dietary advice following your kidney transplant

### Nutrition and transplantation

Following your kidney transplant, many of the dietary restrictions you previously followed may no longer be necessary. You may be unsure of what to eat so the aim of this diet sheet is to answer your questions.

If your new kidney is slow to start functioning, you may need to remain on a restricted diet for a short while. However, as your kidney function improves, you may be able to have more variety in your diet. Your dietitian will advise you on this.

As with any surgery, nutrition plays a key role in your ongoing recovery. For the first six weeks after transplantation it is advised to ensure you have a variety of fruit, vegetables, protein and carbohydrates. This would include a generous portion of lean protein with each meal.

### **Lean protein sources include:**

- Chicken (fat removed)
- Turkey (fat removed)
- Beans/pulses/lentils (no added sugar)
- Tofu
- Meat alternatives e.g. soya mince, Quorn
- Fish
- Eggs (boiled, poached, scrambled)

## **What kind of diet should I be following?**

To get the most out of your new kidney, the emphasis will now be on healthy eating and food safety. Additionally you may need to stop eating certain foods as they can interfere with some of the medication you now need to take.

## **Healthy eating after kidney transplantation**

One of the benefits of a successful kidney transplant is that you can enjoy a more varied diet. Usually, your potassium, phosphate and fluid restriction is lifted, enabling you to eat foods you may previously had to limit.

With fewer diet restrictions, the effect of steroids and an improvement in appetite, you may put on weight. It is a common problem for post-transplant patients to rapidly gain weight. Healthy eating will help you to control your weight and keep your blood levels of cholesterol and other blood fats as near normal as possible. There is also an increased risk of developing diabetes following a transplant, due to the effect of steroids and weight gain. Controlling your weight and cholesterol will help to reduce your risk of heart disease, stroke and diabetes. Including calcium is also important to keep your bones healthy and reduce your risk of osteoporosis (suffering from brittle or fragile bones).

## Healthy eating

Enjoying a healthy diet is all about getting the balance right.

You should select a variety of foods from each of the five food groups in the proportions shown on page 39.

### Tips in following a healthy diet

- Eat regular meals and do not miss meals
- Include starchy foods at each meal. Examples of starchy foods include bread, cereals, rice, pasta and potatoes. Try to choose wholegrain varieties whenever you can
- Eat foods containing fats sparingly and select lower fat options where possible. The nutrition labels on food packaging can help you cut down on total fat and saturated fat; low fat is 3g of fat or less per 100g, low in saturated fat is 1.5g of saturated fat or less per 100g. High fat is more than 17.5g of fat per 100g and high in saturated fats is more than 5g of saturates per 100g
- Limit your intake of added sugar from fizzy drinks, biscuits, cakes, chocolate, desserts etc. You do not need to cut down on sugars found in fruit or dairy products because these foods contain lots of nutrients that are good for us. Nutrition labels tell you how much sugar a food contains. If an item's total sugar content is over 22.5g per 100g, it is high in sugar. Anything under 5g of total sugar per 100g is low
- Eat more fish, including 1 portion of oily fish each week. Examples of oily fish include salmon, mackerel, trout, herring, fresh tuna, sardines, pilchards and kippers
- Aim to eat at least 5 portions of fruit and vegetables a day.
- Eat less salt and salty foods
- Avoid binge drinking and try not to exceed the recommended alcohol limits of 14 units per week for both men and women. Ensure that you spread your drinking over three days or more if you drink as much as 14 units a week
- Prednisolone and some of the immunosuppressive medications can cause your bones to lose calcium in the long run, making them

more fragile and increasing the risk of fractures. Unless your doctor or dietitian tells you otherwise, you should eat more foods rich in calcium. **Examples include:**

- Milk (skimmed or semi-skimmed milk are lower in fat)
- Yoghurts (choose diet or low-fat varieties)
- Cheese (cottage and edam cheeses are lower in fat)
- Tinned fish with edible bones e.g. tinned sardines/salmon
- Dark green vegetables
- Fortified cereals
- Tofu
- Nuts e.g. almonds, brazil, hazelnuts
- Pulses

## Food safety following kidney transplantation

The immunosuppressive medications act on the immune system. Due to their impact, you may have a greater chance of picking up a food-borne illness. For this reason you are advised that after a kidney transplant you should follow the food safety guidelines to reduce the likelihood of food poisoning.

### General food safety

- Frequent and thorough handwashing is vital especially before preparing and eating food
- Avoid cross-contamination during food preparation and storage, and reheat leftovers thoroughly
- Be aware of any food that has been left at room temperature, such as community picnics or buffets
- Processed meats like hotdogs should be avoided or cooked very thoroughly
- Very thoroughly wash or peel vegetables and avoid salad bars at restaurants
- Ensure all foods are consumed within the use by date
- Avoid eating out or takeaways within the first 6–8 weeks after transplantation
- If having a barbecue, to ensure the meat is well cooked, consider

pre-cooking the meat/poultry in the oven first and finishing it off on the barbecue for flavour

- Travelling to developing countries is risky for transplant recipients and should be discussed with your doctor at least 2 months prior to the trip. If travelling, precautions should be taken, these include:
  - Avoid tap water, ice, beverages made from tap water and fresh fruit juice
  - Select vegetables and fruit that can be peeled
  - Hot foods should be served steaming hot
  - Drink bottle or canned and processed beverages
  - Boil tap water if it is to be used

**Some foods may contain harmful bacteria and should be avoided while you are on high doses of immunosuppressive medications (usually for up to 6 months after your transplant):**

- Avoid drinking unpasteurised milk or fruit/vegetable juices/ciders and eating foods made from unpasteurised milk
- Avoid unpasteurised soft cheese like feta, br e and camembert, unless they have been cooked or labelled as pasteurised
- Avoid raw or undercooked eggs, and foods prepared with raw and undercooked eggs such as raw cookie dough or cake batter; and unpasteurised/homemade mayonnaise, hollandaise sauces or caesar salad dressings if made with undercooked eggs
- Avoid raw or undercooked meat, poultry and fish, including shellfish
- Avoid ready to eat foods such as pate, rotisserie chickens and cured meats
- Avoid deli counter meats, fish, poultry - try to buy pre-packaged

## **Drug treatment and diet**

### **Foods that interact with medications**

Some foods, plant compounds and herbal remedies can interact with immunosuppressive medications. It is not recommended to take any 'alternative' medicines (e.g. herbal or homeopathic) or high dose vitamins (e.g. vitamin C) without first discussing this with your transplant doctor or pharmacist.



Food/nutritional supplements may also interact with your immunosuppression medications, if you are considering these, please discuss with your transplant team before taking.

You are advised to avoid grapefruit in any form as this can interact with a number of medications.

If you are prescribed ciclosporin it is also advisable to avoid having large quantities of the following:

- Chamomile and Earl Grey tea
- Seville oranges (often used in marmalade)
- Star fruit

## Thanking your donor family

You may wish to find out a little bit about your donor. To ensure confidentiality of the donor family is maintained we are only able to tell you their approximate age and gender. In time, you may wish to write a letter to your donor's family. The decision to write to your donor's family is a personal choice. It may be the most difficult letter you have had to write. However, it may help you to know that nearly all donor families express appreciation for the cards and letters that they receive from recipients and their families, and occasionally they will write a reply.

### **If you do decide to write a letter or card the following suggestions may help you:**

- Use your first name only
- Mention your family or friends
- Mention your hobbies or interests
- Write about how your lifestyle was affected by kidney failure and its treatment
- Say how long you waited for your transplant
- Explain the benefit of transplantation for your lifestyle and health
- Show how much this means to you and your family or friends
- You may wish to thank your donor's family for the unique gift they

have given you

- Try to keep the language simple and sincere
- Be aware that your donor's family freely decided to donate their loved one's organs to benefit others
- **Do not** mention what area you live in or your hospital
- All letters should be sent to your recipient transplant coordinator for forwarding to the donor family. This is a confidential service.

## Advice and support

Following your kidney transplant, you may find the following Queen Elizabeth Hospital Birmingham support services useful:

### Young Adult Transplant Service

A service aimed at supporting patients aged between 16 and 25 who have had a kidney transplant and are under the care of Queen Elizabeth Hospital Birmingham.

Contact: Young adult support nurse: **07867 180 386**

Youth worker: **07920 807586**

### Queen Elizabeth Renal Psychology Service

Our renal psychology team are available to offer help and support to those in need of emotional and psychological support when coming to terms with renal failure and kidney transplantation.

Contact: **0121 371 4455**

### Patient Advice and Liaison Service (PALS)

The PALS team are available to help you to resolve your concerns, highlight your compliments for our staff, pass on your comments to the right people and answer your enquires in an empathetic, efficient and professional manner.

Contact: **0121 371 3280**

### Renal Dietitian and Nutrition Team

The dietitian team are available for any advice regarding your diet.

Contact: **0121 371 3485**

## Renal Pharmacy Team

The renal pharmacy team are available for advice regarding your medicines. Please contact the outpatient clinic clerks and ask to be put through to the pharmacist.

Contact: **0121 371 5630**

## Other external support groups

### Kidney Patients' Association

The Queen Elizabeth Hospital Kidney Patients' Association (QEHKPA) provides help and support to kidney patients, their carers and family at Queen Elizabeth Hospital Birmingham (QEHB).

The QEHKPA is a registered charity that raises funds for equipment to help improve a patient's experience. The charity also offers support to research projects at QEHB and funds patient outings and holidays.

### Aims of the Kidney Patients' Association:

- Ensure a patient's time at QEHB or dialysis unit is as comfortable as possible by supporting hospital services
- Raise awareness of the need for organ donation
- Increase public knowledge of kidney disease
- Provide information for patients and carers
- Make sure patients' views are heard in the development of treatments and services through the West Midland Renal Network and the National Kidney Federation
- Offer a peer support programme where patients and carers can talk in confidence to other patients and carers
- For more information on the QEHKPA or to share patient experiences, please visit **[www.kidneymatters.co.uk](http://www.kidneymatters.co.uk)**

# Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.



Water, lower fat milk, sugar-free drinks including tea and coffee all count.  
Limit fruit juice and/or smoothies to a total of 150ml a day.

Choose wholegrain or higher fibre versions with less added fat, salt and sugar  
Potatoes, bread, rice, pasta and other starchy carbohydrates



Fruit and vegetables every day  
Eat at least 5 portions of a variety of fruit and vegetables every day

Check the label on packaged foods

Each serving (150g) contains	Energy	Fat	Saturated fat	Salt
	13%	43%	7%	15%

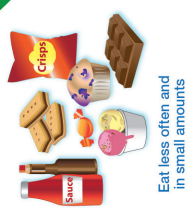
Typical values (as sold) per 100g: 687kJ / 167kcal

Choose foods lower in fat, salt and sugars

Beans, pulses, fish, eggs, meat and other proteins  
Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat

Dairy and natural oils  
Choose lower fat or 0% but not low sugar

Oil & spreads  
Choose unsaturated oils and use in small amounts



Eat less often and in small amounts

Per day 2000kcal

2500kcal = ALL FOOD + ALL DRINKS

Source: Public Health England in association with the Welsh government, Food Standards, Scotland and the Food Standards Agency in Northern Ireland

© Crown copyright 2016

**Renal Department**  
Queen Elizabeth Hospital Birmingham  
Mindelsohn Way, Edgbaston, Birmingham, B15 2GW  
Telephone: 0121 371 2000