

# Your guide to kidney transplantation

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**This booklet aims to answer some of your questions about having a kidney transplant.**

**You will also have opportunities to ask questions and to discuss any of your concerns about transplantation with doctors, nurses and other healthcare professionals. Please let staff know if there is anything you do not understand.**

# Kidney transplantation

## **Kidney transplantation**

Not all patients are suitable to have a transplant. For those people who are suitable a transplant will, in most cases, give you a better quality of life than dialysis. Your kidney team will discuss transplantation with you during your clinic visits. You may need to have several tests and medical examinations to help decide whether you are suitable for a transplant.

These tests and medical examinations are important, as the results help your kidney doctor and transplant surgeon know whether you are in good health and what the risks are to you of the transplant procedure. We will share and discuss all test results, medical examination results and potential risks with you. If the risk to you is thought to be too high you will be advised not to have a kidney transplant.

You will not be put into the transplant waiting pool or put forward for a living donor kidney transplant until you have been assessed as being suitable by one of our transplant surgeons.

## **How are kidneys donated?**

Listed below are the different ways in which kidneys can be donated. The person giving the kidney is called the donor. The person receiving the kidney is called the recipient.

### **Deceased donor transplant**

A deceased donor kidney comes from someone who has died. There is a national pool of people waiting for this type of transplant. You can find out more in the leaflets '**Understanding the kidney transplant pool**' and '**Having a kidney transplant from a deceased donor**'. Please ask for copies.

### **Living donor transplant**

Most people can live a normal life with only one of their two kidneys. Some choose to donate one of their kidneys to a family member or a friend. This is called living kidney donation. You can find out more from the booklet 'Gift of life'. Please ask for a copy.

### **The UK Living Kidney Sharing Schemes**

If a family member or friend would like to donate a kidney to you, ideally they should be compatible with you in terms of blood group and tissue type. If they are not this is known as an 'incompatible' or 'mismatched' transplant. If the person still wants to donate and is healthy you could be paired with one or more incompatible donors and recipients in the same situation so that each donor can donate their kidney to the other donor's recipient. Each recipient benefits from a compatible transplant that he or she would not otherwise have had.

Where two couples are involved this is known as a 'paired' donation and where more than two pairs are involved, this is known as a 'pooled' donation.

All the donor operations are usually scheduled at the same time on the same day but, in exceptional circumstances, it may be necessary to stagger the operations for practical reasons. In this situation, your transplant team will discuss the plans with you so that you are clear about how the swap will work and any additional risks that there may be for you. None of the donors know the person who receives their kidney and recipients will not know the person who donates their kidney.

The UK Blood and Transplant service organise paired and pooled kidney donation. For more information visit [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

### **Altruistic donation**

This is where a person volunteers to donate a kidney to an unknown recipient. The benefit of this type of donation is that a person in the transplant waiting pool receives a living donor kidney and the number of patients waiting in the pool is reduced. This increases everyone's chances of receiving a kidney.

### **ABO and HLA incompatible transplantation**

An ABO (blood group) incompatible transplant takes place between a living donor and a recipient with a different blood group.

An HLA (Human Leukocyte Antigen) incompatible transplant takes place between a living donor and a recipient who has a different tissue type.

It has only recently become possible to do these types of transplants. For the donor the process is the same as for an ordinary transplant but the recipient may need to have different treatments or stronger medications to reduce the risk of transplant rejection. If you would like to know more about this kind of transplant please talk to your transplant team. You may also wish to read our leaflets '**Blood group incompatible kidney transplantation**' and '**HLA incompatible kidney transplantation**'.

### **Kidney and pancreas transplantation**

This may be an option if you have diabetes and kidney failure. There are two options for a kidney and pancreas transplant:

- 1)** A simultaneous pancreas and kidney transplant (SPK). Both organs come from the same deceased donor and are transplanted during the same operation. You may wish to read our leaflet 'Having a simultaneous pancreas-kidney (SPK) transplant'
- 2)** A pancreas after kidney transplant (PAK). You first receive a kidney from a living kidney donor. Several months later you go into the waiting pool for a pancreas from a deceased donor. The wait for a pancreas transplant is about six months. You may wish to read our leaflet 'Having a pancreas after kidney (PAK) transplant'



### **Why might I need a pancreas transplant?**

In your pancreas you have small clusters of cells called islets which produce insulin. When these cells do not work properly they do not produce insulin and you develop diabetes. When a new pancreas is transplanted into someone with diabetes it contains a lot of new islets which are able to produce insulin. After pancreas transplantation most patients with diabetes no longer need insulin injections.

For some patients, it may be more appropriate just to transplant the islet cells rather than the whole pancreas, although this may not completely remove the need for insulin. The transplant team will discuss these options with you.

# Before the transplant

## Should I stop smoking?

Yes! We ask patients who are waiting for a kidney transplant to stop smoking. Smoking harms your heart and increases your risk of developing several types of cancer, lung disease and heart disease. Stopping smoking at any age will improve your health and may increase your life expectancy. Please ask for advice on how to stop smoking from:



- your GP
- your kidney team
- Trust stop smoking service on 020 7188 0995
- Smokefree National Helpline 0300 123 1044.



## Do I need to lose weight?

Being overweight means you are less likely to be suitable for a transplant. We use the body mass index (BMI) to measure your weight relative to your height. If your BMI is more than 30 you may have more problems during your transplant operation. This includes an increased risk of wound infections, deep vein thrombosis (DVT) and blood clots in your lungs.

We encourage you to lose weight if your BMI is greater than 30. Guy's run a weight management clinic for kidney patients where you can get advice on how to lose weight and exercise safely. Once you have lost enough weight you will then have tests and medical examinations to assess if you are suitable for a transplant. You can calculate your BMI using BMI calculators which are available on the internet or in healthy eating booklets.

### **Can I continue to exercise?**

Yes, although there may be some restrictions if you are on dialysis. While you are waiting for a transplant it is important that you stay healthy. Ask your healthcare team for more information.

### **Can I go on holiday?**

While you are waiting for a transplant it is important that you let your healthcare team know if you are thinking about travelling outside the UK. You may be suspended from the transplant list if you travel to a location outside the UK where getting back quickly will be a problem. If you have had haemodialysis in a country where blood-borne infections are common you will be suspended from the transplant list for two months as the transplant medications can be dangerous for people with recently acquired infections. If your hepatitis B and C levels are negative two months after returning to the UK, you will be re-activated on the transplant list.

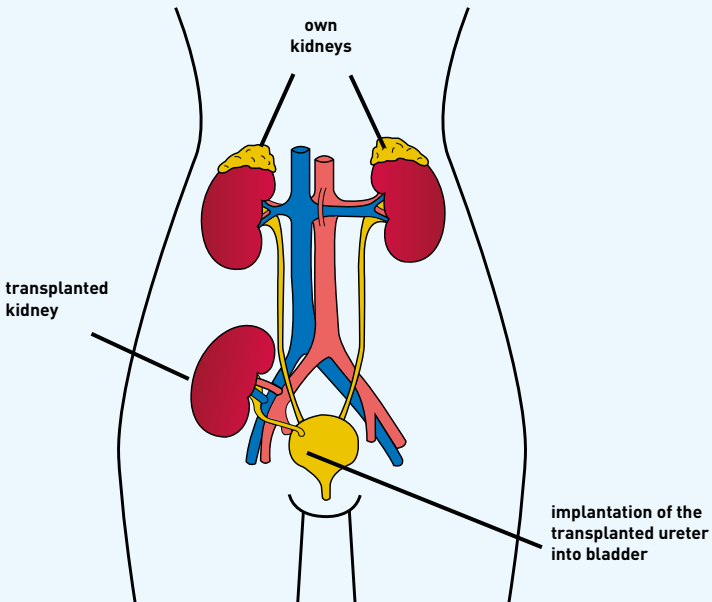
### **Can I have vaccinations for my holiday?**

Before having a kidney transplant you can have travel vaccination as advised by your GP but your body may not be able to respond fully to the vaccines, so you should always take extra precautions. Please ask for advice from your kidney team.

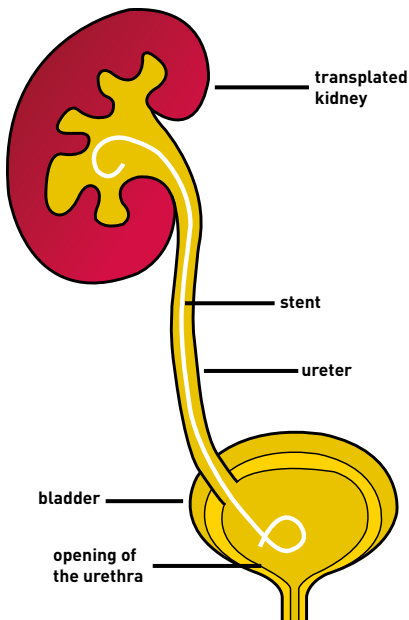
# The kidney transplant operation

## What happens during the kidney transplant operation?

A kidney transplant generally takes two to four hours. A kidney and pancreas transplant generally takes five to six hours. The new kidney will be put into the left or right groin. Your own kidneys are not usually removed during the operation.



The blood vessels of the donor kidney are attached to your blood vessels and the ureter (the tube which connects the kidney to the bladder) is joined to your bladder. A small tube called a stent is placed inside the ureter to make sure you are able to pass urine. Between four and six weeks after your transplant the stent is removed under local anaesthetic as a day case procedure, with no need to stay overnight in hospital.



Occasionally, both kidneys from a deceased donor are transplanted into a single recipient. This is called a double kidney transplant. This will be done if the transplant surgeons and kidney doctors think that transplanting just one kidney would not work well enough for you, usually because the donor is an older person. This will be discussed with you when you come in to hospital.

### **Can I have another transplant if this fails?**

Sometimes a kidney transplant fails. If this happens another transplant will be considered if you are fit or healthy enough. If your transplant fails you might need to have an operation to remove the failed kidney. The success rate for second and third transplants is generally as good as for the first, but you are likely to have a longer wait. You will also need to go through the same tests again to make sure you are fit and healthy enough to have another transplant.

### **Transplant advantages and disadvantages**

Statistically, patients who have had a kidney transplant are likely to live longer than those who remain on dialysis. But having a transplant is not completely without risk. Some of the benefits and risks are listed on the next pages.



## What are the benefits of transplantation?

Having a transplant can make a big change to the quality of your life. There are many advantages to having a transplant including:

- You will not have to rely on dialysis
- You will no longer have to restrict how much fluid you have or follow a special diet. But you should continue to eat healthily
- You should feel more energetic and be better able to cope with your everyday life, your job or your studies. A lot of patients can return to full-time employment
- If you are a woman of childbearing age your fertility is likely to improve - women on dialysis are generally infertile. Your sex life is also likely to improve
- If you have a kidney and pancreas transplant it usually means you will no longer need to take insulin if you have diabetes
- Having a transplant will mean fewer restrictions on your life, for example greater freedom to travel
- You are likely to live longer with a transplant than with dialysis.

## **What are the risks of transplantation?**

All medical and surgical treatments have risks. Although a transplant is likely to increase your quality of life, problems can occur. These problems (also called complications) can occur soon after the transplant, or later on. If you become unwell and are admitted to your local hospital, which may not have a dedicated transplant team, we would advise that you or your relative informs the Guy's transplant team so we can provide specialist advice. Please contact us on 020 7188 5664, Monday – Friday 9am – 5pm, out of hours call 020 7188 7188 and ask for the renal doctor on call.

## **Early complications**

- The kidney may not work straight away. If this happens, you may need dialysis until it begins to work. This may be days, or sometimes weeks after the transplant. Kidneys from living donors almost always work immediately. Kidneys from deceased donors have about a 50:50 chance of working straight away. If the kidney does not work immediately, you will have regular scans and sometimes biopsies to make sure that other problems such as rejection have not occurred.
- Sometimes the kidney transplant never works. This is rare (two – five cases out of a hundred transplants).

- Occasionally, patients need further surgery after their transplant. This may be because of bleeding, infection, or because of problems with the attachments between the kidney and your blood vessels and bladder.
- Rejection is one of the most important risks and this occurs because your immune system recognises the transplanted organ as foreign. To prevent this happening you must always take your prescribed anti-rejection medications as directed by your transplant team. These anti-rejection medications are also known as immunosuppressants.
- You will have a higher risk of infection following transplantation. This happens because the anti-rejection medications lower your immune system. The anti-rejection medications do however prevent your body rejecting your new kidney so without them it may stop working. Your transplant team will monitor you closely to reduce your risk of infection. It is important to continue taking all of your anti-rejection medications despite this risk.
- A pancreas transplant is a longer, more complex operation than having a kidney transplant. About one in three patients who have a pancreas transplant need more surgery soon after the transplant. This might be for bleeding, infections around the pancreas, or for bowel problems.

## Later complications

- If you take steroids (prednisolone) long-term you have an increased risk of osteoporosis. This is a condition where your bones become more fragile. As a result they are more likely to break. Your transplant team will refer you for a bone scan every few years to check the thickness of your bones. This scan is known as a DEXA (dual energy x-ray absorptiometry) scan and you must not miss this appointment.
- A condition called New Onset Diabetes After Transplantation (NODAT) occurs in up to one in five patients in the first year after kidney transplantation. This is a result of the anti-rejection medications and is long term. This is usually treated by diet; some people are referred to a specialist diabetes clinic.
- You will have a higher risk of skin cancer following your transplant because of the medications you need to take. This can be reduced by taking the following precautions before and after your transplant. Other side effects of medications can be found in the Transplant Medications section of this booklet (page 31), together with practical advice on skin care.

- Check your skin regularly to be aware of any changes, such as new moles or changes to existing moles (e.g. they become red or itchy). Your transplant clinic or GP will refer you to your local skin clinic for an annual skin check. You must not miss this appointment as it is very important.
- Avoid direct sunlight on the skin. Always wear sun cream with a high sun protection factor (SPF) – at least 25-30 – when outside between March and October and when travelling in hot countries. This can be prescribed by your GP.
- You will also have a small increase in the risk of getting other types of cancers such as lymph or cervical cancer. It is very important that women have a cervical smear test every three years. Your transplant team will remind you and your GP to arrange this. You must tell the team if you experience any unusual symptoms.

### **Expected survival of the kidney transplant**

Kidney transplants do not last as long as healthy kidneys and many people with kidney failure need more than one transplant in their lifetime. About 80 out of 100 kidney transplants from deceased donors will still be working five years after transplantation. For kidneys from live donors, about 90 out of 100 kidney transplants will still be working five years after transplantation.

The lifespan of a kidney transplant is quite variable as it depends on the age of the donor, the health of the donor, and many other factors such as your age and other medical problems. Ask your kidney doctor and transplant surgeon if you have more questions about this. Individual risks will be discussed with you before you are entered into the deceased donor pool.

### **Other issues around transplant risks**

- The risk of death after a kidney transplant is low, and in the long-term is lower than staying on dialysis. About 95 out of 100 patients who have a kidney transplant are alive one year after the transplant.

# Going into hospital

## **How much notice will I be given about when the transplant will take place?**

If you are having a deceased donor kidney transplant the transplant team will contact you by telephone and you will need to go to Guy's Hospital immediately. All kidney transplants are carried out at Guy's Hospital. If you are waiting for a deceased donor kidney transplant it is important that you:

- Tell your partner, close family or main contact person(s)
- Plan in advance who will look after any dependents including pets
- Have a bag ready with toiletries, night clothes and information about all the medications you are taking
- Plan how you will get to Guy's Hospital, particularly at night and during the weekend.

If you do get the call to have a transplant, you should go to Richard Bright Ward, 6th floor, Borough Wing, Guy's Hospital. The nearest station is London Bridge train and underground station. You should not eat or drink unless advised otherwise by the transplant team.

If you are having a living donor kidney transplant you and your donor will be able to plan the date of your surgery with your transplant team.



### **Can I bring a friend or a relative with me?**

Your close family or friends are welcome to come with you to hospital. They can also wait on the ward while you are having your operation. Visiting times for Richard Bright Ward are 2pm to 8pm, seven days a week. Children are not allowed on the ward without the permission of the nurse in charge.

### **What about my dialysis treatment?**

If you have haemodialysis the transplant team will arrange dialysis for you before your transplant.

If you have peritoneal dialysis (PD) you should continue with your exchanges until the operation. Just before the operation you will be asked to drain out and cap off. Your PD catheter may be removed during your operation. If not it will be removed when we are sure your transplant has been successful (usually between three and 12 weeks later).

### **What tests will I have when I come into hospital?**

It is very important that you are fit and have no infections before you have your transplant. It is also important that you tell your transplant team if you have, or have recently had, an infection or a cold. They will then decide whether your transplant should go ahead. Withholding this information may increase your risk of complications after your transplant.

Before your transplant you will have blood tests to check that:

- You are still compatible with the kidney you are going to receive

- You are fit to have an anaesthetic.

Other tests include:

- An electrocardiogram (ECG), which records the rhythm and electrical activity of your heart
- A chest x-ray.



You may also have other blood tests. The doctors and nurses will give you more information about this. They are happy to answer any questions and explain anything you do not understand.

The transplant surgeon will see you and talk to you about the surgery in detail. The surgeon may need to talk to you about any medical problems that the donor had. You may be suitable for a trial of new treatments for you or your kidney. If you are eligible, you may be approached by a member of the research team who will talk to you about studies that you might wish to take part in. You are not under any pressure to take part in a study, and saying 'no' will not change the care that you will receive.

Sometimes patients waiting for a transplant from a deceased donor are called in but the transplant does not go ahead. If this happens, the surgeon will discuss this with you at the time.

## **What will happen after my transplant?**

You will be given medication and fluids directly into your veins using a central line. This is to help your kidney function and to prevent rejection. A central line is a small tube which the surgeon will insert into one of the veins in your neck while you are having your operation.

You will be given pain relieving medication during the operation. This will continue when you go back onto Richard Bright Ward for as long as needed.

You may also need dialysis for a short time after your transplant until your new kidney starts working. This is more likely if you have had a deceased donor transplant.

## **How will I be monitored after my transplant?**

You will have blood tests every day to check your kidney function and levels of anti-rejection medication. The team will also keep a close eye on your blood pressure, temperature and fluid balance.



### **When will I go home?**

You will usually be in hospital for four to seven days. If you have a pancreas and kidney transplant you are likely to stay in hospital for two to three weeks.

### **What will happen after I leave hospital?**

After discharge you will have a follow-up appointment at your transplant clinic within one or two days. We will give you the day and time of the appointment before you leave hospital.

After receiving your new kidney you will need to attend the transplant clinic three times a week for the first month, then twice a week for the second month, then once a week until four months. These clinic appointments are important because your risk of transplant rejection or infection is highest during the first few months and the transplant team will need to monitor you closely.

### **What about my transplant medications?**

You will be given your new medications to manage yourself while in hospital, so that you will feel confident about managing your medication at home. Before you go home the ward pharmacist or nurses will give you written information about your new medication, including when and how to take them. Please ask if you are uncertain about any of the medications you are taking.



When you leave hospital you will be given enough medication for at least two weeks. After this the hospital will continue to provide your anti-rejection medication, either through collection from the on-site hospital pharmacy or a home delivery service. Ask the transplant team for further details.



When you come for your first transplant clinic appointment, please remember to bring all your medication with you. This includes those prescribed by the transplant team, those prescribed by your GP and any that you may have bought for yourself from the chemist. After your first visit you must bring an up to date list of your medication with you to every clinic appointment. We need to keep an accurate record of all your medications and we will also advise you about which medicines you can and cannot take.

Please make an appointment with your GP as soon as possible after leaving hospital because your GP will need to prescribe everything other than your anti-rejection medication. It is important that you do not run out of medication. The transplant team will keep your GP updated about all your medications and will notify your GP of any changes.

# Transplant medications

After your transplant you will be taking a variety of new medications and some of your old medicines will be stopped. Some new medications may only be required for a short time or the doses may vary. Others may be required for the rest of the life of the transplant. If you have any side effects or other problems with your medications please talk to your transplant team. You must not stop taking any medications prescribed for you without first talking to your transplant doctor or nurse. Please also read the manufacturer's leaflet inside the pack for more information about side effects and interactions with other medications. However, do talk to the transplant team first.

### **Anti-rejection medication (immunosuppressants)**

The body's immune system recognises a transplanted kidney as 'foreign' and may try to attack it. When this happens rejection occurs. Rejection can happen any time after a transplant and to prevent this you will be prescribed immunosuppressant (anti-rejection) medication. It is essential that you take this medication exactly as instructed because your body's defence system has a good memory and will never forget that the kidney is 'foreign'. If the anti-rejection medicines are ever stopped, your body's defence system may attack and reject the transplanted kidney. While you are in hospital you will be given this medication to take yourself so that you become confident enough to manage your medication at home.

Side effects of immunosuppressants include:

- An increased risk of infection
- A greater risk of getting skin cancer. Check your skin regularly to be aware of any changes. Your transplant clinic or GP will refer you to your local skin clinic for an annual skin check.

Avoid direct sunlight on the skin. Always wear sun cream with a high sun protection factor (SPF) - at least 25-30 - when outside between March and October and when travelling in hot or sunny countries. This can be prescribed by your GP.

Other types of cancer, for example lymph node cancers (lymphomas), are also more common in transplant patients. If you notice any unusual swellings or anything else you are concerned about, you must tell the doctor or nurse in your transplant clinic.

Most patients are prescribed the following immunosuppression drugs:

- Tacrolimus
- Prednisolone
- Mycophenolate.

Not all of these medicines are suitable to be taken during pregnancy. If you are pregnant or are planning a pregnancy, please speak to your doctor.



If you are worried about any of the possible side effects mentioned, please speak to the kidney team. They will be able to give you further information.

## **Tacrolimus**

After your transplant, you will be prescribed tacrolimus. This drug prevents rejection. On the morning of your transplant clinic visits do not take your dose of tacrolimus until after your blood has been taken. This will allow your transplant team to measure the tacrolimus blood levels to make sure that your dose is correct. If you take too high a dose your kidney may be damaged; if you have too low a dose your risk of kidney rejection is increased. We usually contact you by telephone to advise you about any dose changes.

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

Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are detailed below.

- You may become shaky if the level of tacrolimus in your blood is very high
- Tacrolimus increases your risk of developing diabetes following your transplant
- Tacrolimus can cause diarrhoea which may last more than a day. If this happens please contact the transplant team for advice.

Certain tablets or food interfere with tacrolimus including: some antibiotics; epilepsy medications; some heart tablets; oral contraceptives; some pain killers; over-the-counter medicines; herbal remedies; Seville oranges; grapefruit and grapefruit juice. Therefore you must always check with the transplant team before taking any new medications.

Different brands of tacrolimus may result in different levels of the drug circulating in your blood stream. Because of this it is important that once you have been prescribed a particular brand of tacrolimus you do not change to a different brand unless specifically told to do so by the transplant team.

Prograf® and Adoport® are different brands of tacrolimus. These brands of tacrolimus should be taken every 12 hours, for example at 9am in the morning and 9pm at night. By taking tacrolimus at regular intervals, the level of tacrolimus remains stable in your body.

Advagraf® is a slow-release brand of tacrolimus. It is taken once a day in the morning. This should be taken at the same time every day to ensure the levels of tacrolimus remain stable in your body.

## **Ciclosporin**

Ciclosporin is sometimes prescribed instead of tacrolimus. This drug also prevents rejection. On the morning of your transplant clinic visits do not take your dose of ciclosporin until after your blood has been taken. This will allow your transplant team to measure the ciclosporin blood levels to make sure that your dose is correct. If you take too high a dose your kidney may be damaged; if you have too low a dose, your risk of kidney rejection is increased. We usually contact you by telephone to advise you about any dose changes.

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

Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are detailed below.

- You may become shaky if the levels of ciclosporin in your blood are very high
- Ciclosporin can make your gums sore and swollen, so good dental hygiene and regular visits to your dentist are important
- Ciclosporin may result in excessive hair growth. Please speak to your transplant team if this becomes a problem.

Certain tablets or food interfere with how your body handles ciclosporin including: some antibiotics; epilepsy medications; some heart tablets; oral contraceptives; some painkillers; over-the-counter medicines; herbal remedies; Seville oranges; grapefruit and grapefruit juice. Therefore you must always check with your transplant team before taking any new medications.

Different brands of ciclosporin may result in different levels of the drug circulating in your blood stream. Because of this it is important that once you have been prescribed a particular brand of ciclosporin that you do not change to another brand unless specifically told to do so by the transplant team.

Neoral® is a brand of ciclosporin. Ciclosporin is taken every 12 hours, for example at 9am in the morning and 9pm at night. By taking it at regular intervals the level of ciclosporin remains stable in your body.

### **Sirolimus**

Sirolimus is rarely used as an anti-rejection treatment during the first few months after the transplant, but may be prescribed at a later stage for some patients. This is a different type of anti-rejection medication to ciclosporin and tacrolimus. You should not take your dose of sirolimus on the morning of your clinic visits until after your blood has been taken.

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

Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are detailed below.

- Wounds and cuts may take longer to heal.
- It may raise your blood cholesterol levels.

Sirolimus has its own advantages and disadvantages. If your transplant team thinks you may benefit from taking sirolimus they will discuss this with you.

Do not eat grapefruit or drink grapefruit juice while taking ciclosporin, tacrolimus or sirolimus as this may affect your blood levels and may cause serious toxicity and side effects.

## **Prednisolone**

Prednisolone is a steroid used to prevent transplant rejection. It is a good anti-rejection medicine but it does have some side effects. These can be a nuisance but are generally reversible. Your transplant team will try to minimise your dose of prednisolone to minimise these side effects. Where appropriate your transplant doctors will try to discontinue your prednisolone treatment within the first year following your transplant.

We do not recommend that transplant patients take enteric-coated prednisolone tablets, which have a red sugar-coating, because the absorption is less reliable than the non-sugar coated medication. If your pharmacist supplies you with enteric-coated tablets, you should ask them to supply you with the non enteric-coated ones.

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

Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are detailed below.

- Your appetite might increase and you may gain weight
- The shape of your face may appear more rounded
- You may have mood changes if you are taking a high dose
- Your skin may become thin and you may bruise more easily
- You may develop acne (spots)
- You may develop high blood pressure and high cholesterol
- Your blood may become thinner
- You may develop diabetes
- You may develop osteoporosis (fragile bones) in the longer term.

All transplant patients on prednisolone must carry a steroid card which details your steroid treatment. You must show this card whenever you see a doctor, dentist or pharmacist in case of an emergency. The pharmacy will give you your steroid card when you collect your medication.

## **Mycophenolate mofetil (Cellcept®), mycophenolate sodium (Myfortic®) and azathioprine**

Mycophenolate mofetil, mycophenolate sodium and azathioprine are anti-rejection drugs that all work in a similar way and patients can sometimes switch between them under the supervision of the transplant team.

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

Always read the manufacturer's information leaflet which is supplied with the medicine. Some common side effects are detailed below.

- These drugs all suppress your bone marrow. This means you may have a low white cell count, anaemia or a lower platelet count and this means you will be slightly more vulnerable to infection.
- You may experience stomach cramps, diarrhoea or sickness. Reducing the dose or sometimes changing the medication can reduce these side effects.

Mycophenolate is harmful in pregnancy. Women of child bearing age must use effective contraception during treatment. Men who want to start a family should talk to their transplant doctor about whether or not they need to stop mycophenolate.

You should not take allopurinol (a medication to prevent gout) if you are taking azathioprine unless specifically advised to do so by your kidney doctor. If you suffer from gout you should speak to your transplant team.

### **Other medication**

During the first few months after your transplant you will need to take several other medications as well as immunosuppressants.

Please refer to the manufacturer's leaflet within the pack for information on side effects and interactions with these medications.

### **Nystatin mouthwash**

This mouthwash prevents oral (mouth) thrush. You need to rinse your mouth with this, holding it in your mouth for as long as possible before swallowing. This should be done four times a day after meals.

### **Ranitidine**

You will be prescribed ranitidine to reduce the risk of stomach inflammation from other medications.

### **Co-trimoxazole**

You will take this antibiotic during the first year to prevent a particular infection called pneumocystis pneumonia (PCP). This chest infection is caused by a common yeast or fungus called pneumocystis which is usually harmless to healthy individuals. However, in individuals with immune systems weakened due to immunosuppressive drugs it can cause a severe pneumonia. Taking co-trimoxazole can prevent this, and can also prevent a number of other infections including urine infections.



## **Aspirin**

You will need to take aspirin after your transplant to help prevent blood clots. Your transplant team will tell you how long you need to take it for.

## **Isoniazid**

This medication is used to prevent tuberculosis (TB) infection and is given to patients who have a high risk of developing it. When you are taking this medicine, you will also need to take pyridoxine.

## **Pyridoxine**

Pyridoxine is vitamin B6. This prevents one of the most common side effects of isoniazid – peripheral nerve damage or neuropathy. Patients with this condition may experience numbness or pins and needles in the hands or feet, sensitivity to touch or muscle weakness.

Please tell the transplant team if you have been in contact with someone who has TB.

## **Sodium bicarbonate and phosphate supplements**

After your transplant your kidney may not be able to concentrate urine properly. It often takes a few weeks for this to settle down and during this period you may pass a lot of urine, particularly during the night. You may lose a lot of bicarbonate and/or phosphate in your urine and you may need to take supplements to replace this. If you have had a kidney and pancreas transplant you are particularly likely to need sodium bicarbonate supplements.

## **Valganciclovir and ganciclovir**

These drugs prevent and treat viral infections, particularly those caused by a particular type of virus called cytomegalovirus (CMV). You may be prescribed one of these drugs depending on your risk of developing CMV or if the virus is detected during routine blood tests. You may need to take it for up to three months but please do not stop taking it without first talking to your kidney team.

Valganciclovir and ganciclovir are harmful in pregnancy. Women of child bearing age should use effective contraception during treatment. Men should use a barrier method of contraception (condom) during, and for three months after treatment.

## **Antibiotics**

Some patients have recurrent water infections or urinary tract infections (UTI) following transplantation. To manage these, your transplant team may prescribe a small daily dose of antibiotic to prevent the infection returning. You may be given different antibiotics to take month by month. It is very important that you do not stop taking these antibiotics unless instructed to do so by your transplant team.

Please also be aware that some antibiotics can interact with ciclosporin and tacrolimus. It is therefore very important to check with the transplant team before taking any new medication prescribed by other doctors, even by your GP. Erythromycin, clarithromycin and ciprofloxacin are commonly prescribed antibiotics which interact with ciclosporin and tacrolimus. You must check with your transplant team before taking these medications.

### **Will I need to carry on taking my blood pressure medication?**

If you have high blood pressure after your transplant you will be given medication to lower it. Some of the anti-rejection medication may cause your blood pressure to rise. If you needed blood pressure medication before your transplant it is likely that this will need to continue and your transplant doctors will advise you about this. At your clinic visits we will check your blood pressure and weight. It is important to keep good control of your blood pressure as this will help to keep your kidney and body healthy.

Please talk to your transplant team or your GP before you stop taking any medication, as stopping medication suddenly can in some cases be harmful.

### **Are there any medications I should avoid?**

It is particularly important to avoid certain types of painkiller called non-steroidal anti-inflammatory drugs (NSAIDs or anti-inflammatories), such as Ibuprofen (Nurofen®). There are other medications which may be unsuitable, including herbal remedies and over the counter medications. Please speak to your kidney pharmacist, nurse or doctor before taking any medications.

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

You might be able to get free prescriptions if you:

- receive certain benefits
- are on a low income
- have a fistula for haemodialysis
- are aged 60 or over
- have diabetes mellitus, except where treatment is by diet alone
- have a valid medical exemption certificate. These are issued on application to people with diabetes mellitus or have a fistula for haemodialysis requiring a continuous surgical dressing. To apply for a medical exemption certificate ask your doctor for an FP92A form.

There are other reasons why you may get free prescriptions. You can find out more by speaking to your local pharmacist or visiting [www.nhsbsa.nhs.uk](http://www.nhsbsa.nhs.uk)

# Going home

When you get home after your transplant there are some things that you will be asked to do. These include:

- Drinking two to three litres of fluid to keep your new kidney hydrated. It is also important that you keep a note of how much urine you pass
- Being aware of cloudy or smelly urine or pain when going to the toilet. This may mean that you have a water infection (UTI)
- Being aware of other signs of infections such as fever, lethargy and unusual tiredness.

If you do think you have an infection or there is something else wrong, you should contact your transplant clinic.

### **Out of hours you should contact**

Richard Bright Ward at Guy's Hospital. Telephone: 020 7188 8817.

Please do not come to the ward without contacting us first.

### **How often do I need to attend clinic?**

Immediately after the transplant you will need to attend your transplant clinic three times every week for the first month. Once you are stable your visit frequency will gradually reduce and eventually we will only need to see you once every three to six months.

At the clinic you may be invited to participate in research studies related to your transplant or kidney disease. Before you decide, it is important that you understand the purpose of any study and what it will involve; you will be given written information and the chance to discuss it with your doctor. It is entirely up to you whether you wish to take part in research studies, and your care will not be affected should you choose not to participate.

### **Can I continue to exercise?**

For three months after your transplant you should avoid strenuous exercise. You should also avoid contact sports such as rugby or martial arts. We encourage you to have an active lifestyle after your transplant. Your doctor will tell you when you can restart sport and exercise.



## The Transplant Games

The British Transplant Games take place annually in a different UK venue, over four days in the summer. From these Games a team is selected to represent Great Britain in the World Transplant Games which takes place every two years. Participants can compete in a variety of sports from athletics, swimming, badminton and tennis to bowling, snooker and darts.

The aim of The Games is to encourage transplant patients to regain fitness and to promote friendship, whilst increasing public awareness of organ donation.

Some people compete to win medals, others go along to participate in their sport at their own pace and generally enjoy a few days of fun and sharing. For further information please ask the transplant team; or visit: [www.transplantsport.org.uk](http://www.transplantsport.org.uk)

The Guy's and St Thomas' Kidney Patients Association support the Guy's Transplant Games Team, please visit: [www.gsttkpa.org](http://www.gsttkpa.org) for details.



## Do I need to eat a different diet after my transplant?

One of the benefits of a successful transplant is that you can start to enjoy a less restrictive diet again. You will no longer have to follow a fluid restriction but during the first few weeks after your transplant you may need to maintain some dietary restrictions. Your dietitian will advise you about this.



Most patients with a functioning kidney will not need to restrict the amount of potassium in their diet but a small number of patient will need to for a short period of time. Sometimes phosphate levels can drop after a transplant so some people will need to follow a high phosphate diet for a short period of time.

In the long-term, a healthy diet is important. This includes eating foods which are low in fat, sugar, salt, and high in fibre. You are still advised to avoid salt as a diet low in salt will help control blood pressure. 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 which can reduce the risk of heart disease and stroke. Avoiding fatty foods is especially important as the medication you need to take after your transplant may increase your cholesterol level and you may gain weight more easily.

As the immunosuppressive medications can make you more vulnerable to food poisoning, it is important that you follow food safety advice carefully:

- Store and prepare cooked and raw foods separately
- Keep to use-by dates
- Avoid uncooked eggs and unpasteurised cheese
- Thoroughly cook all meat, especially pork, before eating it
- Wash your hands after touching uncooked meat or meat products.

The government's food standard's 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.

Keeping hands clean is one of the government's recommendations for good food hygiene. Wash your hands before:

- eating
- handling raw food
- handling bins or rubbish
- handling pets
- and after going to the toilet.

## Cooking

Thorough cooking kills harmful bacteria in food, therefore it is extremely important to make sure that food is cooked properly. When cooking or reheating food, always check that it is steaming hot throughout.

## Chilling

Chilled foods need to be kept chilled to keep them safe to eat. Keep fridges between a temperature of 0 – 5 degrees Celsius.

## Avoid cross contamination

Cross-contamination is when bacteria spreads between food, surfaces or equipment. It is most likely to happen when raw food touches (or drips onto) ready-to-eat food, equipment or surfaces.

## Avoid high risk foods

The following should be avoided for the first six months after your transplant:

- Raw meat, poultry and shellfish
- Unpasteurised soft cheeses and blue veined cheese
- Anything probiotic, for example, probiotic yogurt or probiotic capsules
- Any yogurts with the word 'bio' on the label
- Raw egg and runny eggs
- "Slush Puppies", ice cream from ice cream vans and other softserve machines (for example 'Mr Whippy')
- Foods from salad bars and deli counters
- Unwashed fruits, vegetables and salad.

After your transplant, the dietitian will review you and discuss this information in more detail.

## Can I drink alcohol?

Yes, as once you have had a transplant you will no longer need to restrict your fluid intake. However the NHS recommendations are:



- Men and women are advised not to regularly drink more than 14 units a week.
- Spread your drinking over three days or more if you drink as much as 14 units a week.
  - Pint of normal strength beer = 2.3 units of alcohol
  - Medium (175ml) glass of wine = 2.3 units of alcohol
  - Single (25ml) measure of spirit = 1 unit of alcohol

### **Will I be able to go on holiday?**

For the first four to six months after your transplant, you will have frequent clinic appointments so going away may be difficult. If you are planning a holiday within the first six months after your transplant, please talk to a member of your transplant team before making any arrangements.

The usual advice is not to go abroad for the first year after transplantation. If you do go on holiday please make sure you have enough medication for your trip, with some extra in case of an emergency. You should carry all your medication, a letter from the transplant clinic with information about your medication and your steroid card in your hand luggage. Ideally, you should not buy over the counter medicines while abroad.

### **Can I have vaccinations for my holiday?**

Yes, providing they are suitable, but you may not fully respond to the vaccines given because of your anti-rejection medications. You may need to take extra precautions. Please make sure you give yourself plenty of time to find out about vaccinations before you go away. You will need to contact your GP to arrange any vaccinations or visit a travel clinic.

After your transplant, you must avoid live vaccines. Always check with your transplant team before having any vaccinations. Check the list on the next page to see which vaccinations you can and cannot have. This list is not exhaustive; always ask your kidney doctor or nurse if you are unsure.

### **Live vaccines - not suitable**

Yellow fever

Live oral typhoid

MMR (measles, mumps, rubella)

Smallpox

Live oral polio

BCG (Bacillus Calmette-Guérin)

Varicella zoster

### **Suitable vaccines**

Inactivated polio

Influenza (types A and B)

Hepatitis A

Hepatitis B

Pneumococcal

Diphtheria, tetanus and inactivated polio

Polysaccharide Typhoid

Meningococcal

We advise you not to travel to countries where there is a risk of catching malaria after your transplant. If you need to take malaria medication, please talk to your kidney doctor and your pharmacist.

### **Will I still be able to work?**

We suggest you take about two to three months off work after your operation. How long you take off will depend on the type of job you do and how quickly you recover. The doctor you see in the clinic after your operation will be able to advise you about when you can go back to work. Your GP can give you any medical certificates you may need.



### **Will I be able to drive?**

Most people will be able to start driving again within four to six weeks of having their transplant but you should check first with the transplant team.

You should also contact your insurer to check when you are insured to drive after the operation.

### **When will I be able to start having sex again?**

When you feel well and comfortable enough – there is no specific time.

### **What contraception should I use?**

After a transplant many patients become more fertile. If you are a young woman and wish to avoid pregnancy you must use some form of contraception and there are many choices available. The pill (oral contraceptive) is safe to use, but can interfere with blood pressure control and some can increase the risk of clotting. Please talk to your GP or transplant doctor before taking it. Implants and injections are also safe and effective. Condoms, foams or diaphragms are safe but less effective in preventing pregnancy. However, these methods of contraception also help protect you from sexually transmitted infections, including chlamydia, gonorrhoea, HIV and hepatitis. Please discuss this with the transplant team. Standard coils are not recommended for women who are on immunosuppressive drugs, but the Mirena IUS is both safe and highly effective.

### **Can I get pregnant after my transplant?**

Women of child bearing age are usually able to conceive after a transplant, but we suggest you wait one year before trying for a baby. This will give your body time to adjust to the new kidney and medication. It is important that you talk to your kidney doctor before you start trying for a baby. You may need to change some of your medications before you become pregnant. During your pregnancy the kidney and pregnancy (obstetrics) healthcare teams will closely monitor you and your baby.



## **Will having a transplant affect my sex drive?**

You may experience less interest in sex before your transplant. Men may have difficulties getting and keeping an erection and in women orgasms may be less frequent.

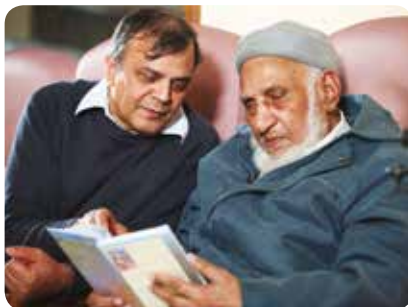
Some of these problems may improve after your transplant and some may continue. If you are having problems please talk to a member of the healthcare team who can offer advice and treatment.



**More information,  
contact details and  
support services**

### **Do you have any information about being a living donor?**

The transplant team supports living donors as well as kidney patients. The booklet '**Gift of life**' gives more information. Please ask for a copy.



### **Will I be able to contact the donor family?**

If you have had a deceased donor transplant you will not know the donor. But at some point after your transplant you may wish to contact the family. This can only be done anonymously. You can give a letter to your transplant co-ordinator who will pass it on to the family.

### **Can I talk to someone who has had a transplant?**

Guy's offer peer support to all kidney patients. You may wish to speak to someone who is also waiting for a transplant, someone who has had a transplant or someone who donated a kidney. Ask for a copy of our leaflet '**Peer Support for kidney patients**'.

**Kidney Services at  
Guy's Hospital:**

**Kidney Clinic**  
4th Floor Tower Wing  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT  
Tel: 020 7188 5664

**Living donor co-ordinator:**  
Tel: 020 7188 5688

**Transplant pool coordinator:**  
Tel: 020 7188 9391

**Guy's and St Thomas' website**

Transplant section – includes information on live donor kidney transplantation, pancreas transplantation and surgery to form access for haemodialysis. [www.guysandstthomas.nhs.uk/our-services/transplant/overview.aspx](http://www.guysandstthomas.nhs.uk/our-services/transplant/overview.aspx)

Kidney section – all of our kidney and transplant information leaflets are listed here and can be read on-line or downloaded. [www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx](http://www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx)

**Peer support**

Peer support aims to provide practical, emotional and social support for people with kidney disease and their families. It provides an opportunity to talk to an experienced kidney patient on a one-to-one basis.

Tel: 020 7188 7924

**Psychologists**

Psychologists offer support to kidney patients and donors

Tel: 020 7188 5969

**Social workers**

Can help you by providing support, advice and information on finances, work and practical help at home.

Tel: 020 7188 5684/4023

**Patient Advice and Liaison Service (PALS)**

The Patient Advice and Liaison Service (PALS) offers support, information and assistance to patients, relatives and visitors. The PALS team can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. Ask a member of staff to direct you to the PALS office or:

Tel: 020 7188 8803

e: [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

## **Language and Accessible support services**

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

Tel: 020 7188 8815

## **Other Resources**

### **Guy's and St Thomas' Kidney Patients' Association**

[www.gsttkpa.org](http://www.gsttkpa.org)

### **Kidney Care UK**

**(previously British Kidney Patient Association)**

Tel: 01420 541424

[www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

### **Kidney Research UK**

Tel: 0300 303 1100

[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

### **National Kidney Federation**

Tel: 0845 601 02 09

[www.kidney.org.uk](http://www.kidney.org.uk)

### **NHS Blood and Transplant**

**(organ donation and transplantation)**

Tel: 0117 975 7575

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

**Diabetes UK**

Tel: 0345 123 2399

[www.diabetes.org.uk](http://www.diabetes.org.uk)

**Transplant Support Network**

Tel: 0800 027 4490 or

0800 027 4491

[www.transplantsupportnetwork.org.uk](http://www.transplantsupportnetwork.org.uk)

**Mykidney website**

A website to help people understand more about kidney disease and how to live with it. [www.mykidney.org.uk](http://www.mykidney.org.uk)

**Patient View**

PatientView is a free online resource for kidney patients. If you register at the kidney clinic you will receive a username and password that will enable you to see your personal blood test results online. It also provides information about kidney conditions and treatments. [www.patientview.org](http://www.patientview.org)

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