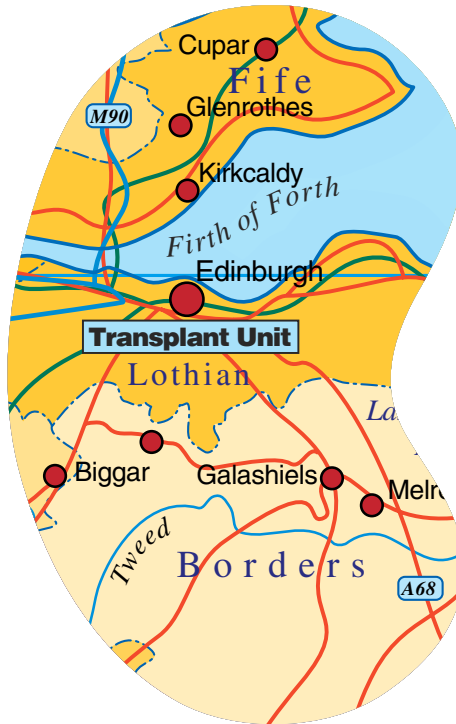


Transplant Guide

Transplant Unit
Royal Infirmary of Edinburgh
Lothian University Hospitals NHS Trust



Kidney Transplant

Your Questions Answered

Part 1

Introduction

Welcome to the Renal Transplant Unit of the Royal Infirmary, Edinburgh.

The first kidney transplant performed in the Royal Infirmary was in 1961 and indeed this was the first successful kidney transplant in the United Kingdom. Since that time many hundreds of patients have experienced the benefits of kidney transplantation in the Edinburgh Renal Transplant Unit.

On the 5th of June 1995 the Renal Transplant Unit joined with the Scottish Liver Transplant Unit, so that the efforts of the transplant surgeons, doctors, nurses and other staff could be combined.

Within this booklet we are trying to provide information for patients awaiting kidney transplantation, those about to receive a transplant and families and friends of renal patients. We are very keen that patients get a chance to visit the Unit long before a transplant is performed, so that they may ask any questions or tell us of worries that they may have.

The information in this booklet is a basic guide only. Please contact us if you wish to know any more.



Useful contact numbers:

0131 536 3946 Transplant co-ordinators office
0131 536 3776 Patient enquiries/ out of hours contact number
0131 536 1000 RIE Switchboard
0131 536 3286 Renal social workers

The Transplant Unit Staff (Royal Infirmary of Edinburgh)

Consultant Surgeons	Professor James Garden Mr. John LR Forsythe Mr. Murat Akyol Mr. KK Madhavan Mr. Henry Pleass
Consultant Physicians	Dr. Robin Winney Dr. Liam Plant Dr. Caroline Whitworth Dr. Alan Cumming Professor Neil Turner Dr. Richard Phelps Dr. Charles Swainson
Transplant Co-ordinators	Miss Jackie Bradie Mrs. Moira Doyle Miss Jen Lumsdaine Mrs. Irene Russell (Dundee)
Senior Nursing Staff	Mrs. Lesley Logan Sr. Sarah Lundie Sr. Caroline Stephenson

What happens when a kidney becomes available?

When a kidney becomes available, someone from the transplant team will contact you and ask you to make your way to the transplant unit at the RIE. This call may happen at any hour of the day or night.

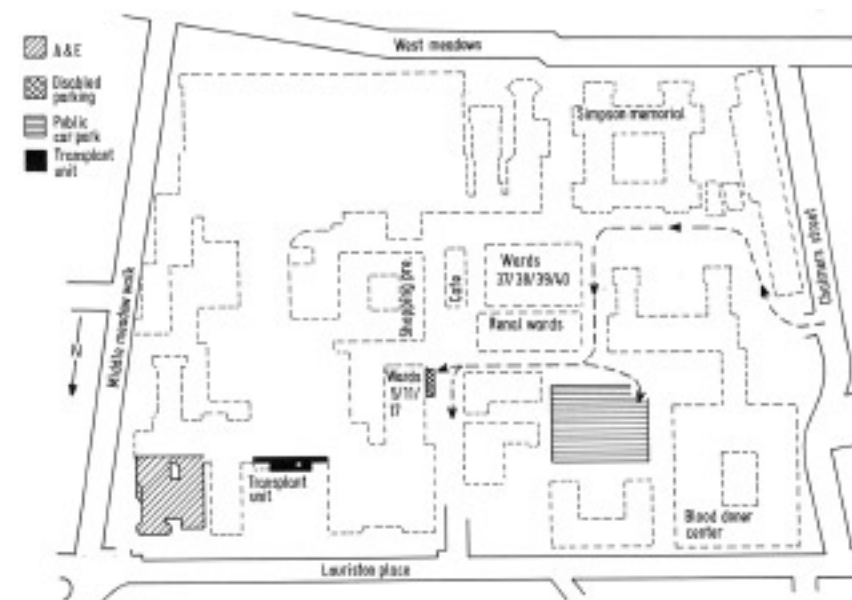
(Remember that the only entrance open from 2200 - 0700 is at Accident and Emergency.)

You will be asked:

1. If you are fit and well
2. Where and when you last dialysed
3. To have nothing more to eat and drink

Is there car parking at the hospital?

Unfortunately parking spaces are very limited at the Royal Infirmary. During the day it is only possible to park in the hospital grounds for a very short period to allow your relative to escort you to the transplant unit and see you settled. There are two fee-paying car parks at the hospital, and in the evening it is usually possible to park in the grounds or surrounding streets.



Who will I meet?

Some of those responsible for your care include:

Doctors - a medical team of surgeons, physicians, anaesthetists and radiologists will look you after. Some of them you may already know from outpatient clinics or previous hospital admissions. As the Royal Infirmary of Edinburgh is a Teaching Hospital, you will come across junior as well as senior doctors and, perhaps, medical students.

Nurses - During your operation you will be looked after by theatre staff. On your return to the Transplant Unit your care will be planned and carried out by nursing staff who work in teams as this ensures the best possible standard of care for our patients.

Transplant Co-ordinators - You will have met at least one of the transplant co-ordinators before your admission. As they are based in the Transplant Unit, you will be sure to meet them again during your hospital stay.

Physiotherapist - If time allows, you will be seen by a physiotherapist before you go to theatre, but this is not always possible. You will certainly meet them after your operation and they will explain the importance of breathing exercises and early mobilisation.

Dietitian - You will already have had contact with a dietitian and will be seen by the renal dietitian during your stay. The dietitian will ensure that you eat well during your recovery from the operation.

Pharmacist - Throughout your stay your medications will be reviewed by the doctors and pharmacist. The pharmacist will discuss your drugs in detail and answer any questions you may have.

Chaplain - The Royal Infirmary has a number of chaplains of different denominations who are on hand to offer support to any patient or their relatives in a general way, while offering religious and spiritual help. The chaplains can also arrange support for those of our patients who are not members of the Christian faith. Please do not hesitate to ask for a visit if they can be of any help to you or your family.

Social Worker - A social worker is available to assist you and your family with matters of a psychosocial or financial nature and will be happy to visit you on the ward if you so wish. You will already have met one of them before or during your spell on dialysis. Many of the questions asked by patients whilst they are in the hospital concern welfare benefits. A few general guidelines are listed on pages 27-28. If you are in doubt about your eligibility to benefits, please check with your local DSS office or speak with one of the renal social workers.

What is the self medication programme?

After your transplant, when you are ready, you will have the opportunity to participate in the self-medication programme that operates on the Transplant Unit. It is designed to give you practical information about your medicines and how to take them whilst you are still in hospital. The nursing staff and pharmacist ensure that by the time you are ready to go home you feel confident that you know all about your medications and their possible side-effects.

What is the annual review?

Around the anniversary of your transplant operation, you will be sent an appointment for a review. You will be seen by one of the transplant co-ordinators who will give health advice, take bloods for cholesterol, 24hr urine collection, skin checks and will discuss any issues of concern.

Do you have a web site?

Yes. <http://renux.dmed.ed.ac.uk/EdREN/Unitbits/TransplantUnit.html>

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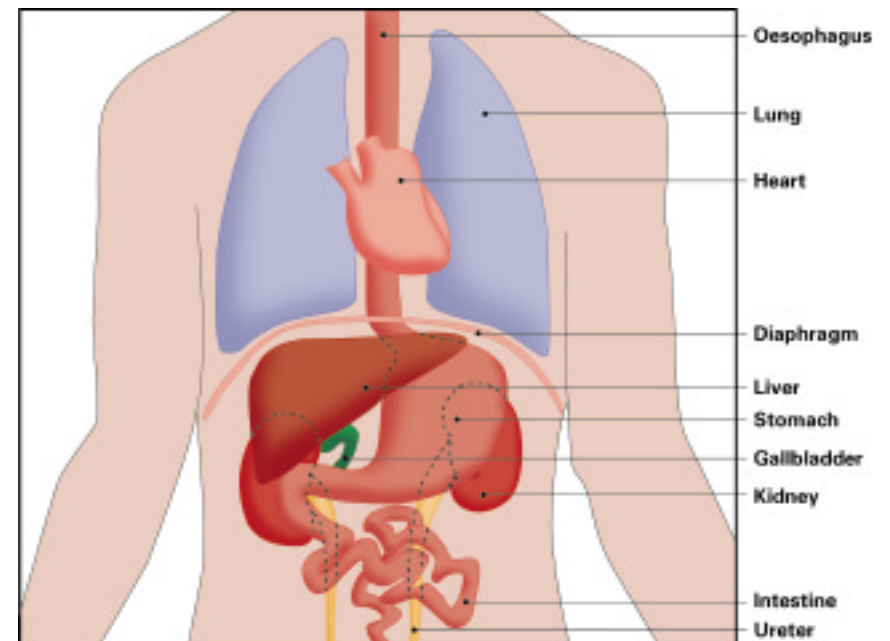
Part 2 - Live Kidney Donation

Part 1

The Kidney

What is the kidney?

The kidney is bean shaped. We have two kidneys situated just above the waist towards the back, one on each side of the spine. Each kidney is embedded in fatty tissue that serves as protection.



What does the kidney do?

The overall function of the kidney is to make urine, but the kidney is also involved in other jobs:

1. Excretion of harmful substances that would otherwise build up in the blood stream
2. Regulation of body water
3. Regulation of body salts such as sodium and potassium
4. Regulation of blood pressure
5. Production of red blood cells by the bone marrow
6. Affects the amount of calcium in the bones

What happens when the kidneys fail?

Renal failure is due to progressive disease of both kidneys resulting in damage of kidney tissue.

As renal function is lost, the following problems can (though do not always) develop:

- Tiredness
- Swelling
- Breathlessness
- Anaemia
- Loss of appetite
- Nausea
- Itch
- Loss of libido, impotence, reduced fertility
- Anxiety, frustration, depression

What are the benefits of kidney transplantation?

Kidney transplantation offers the chance to lead a nearly normal life with:

- Freedom from dialysis
- Improved capacity to socialise and enjoy life to the full
- Return of strength and energy
- Freedom from dietary restrictions
- No restriction on physical activity (except contact sports)

What are the disadvantages of kidney transplantation?

- Risk of failure
- Infection
- Malignancy
- Diabetes
- Side effects of drugs necessary for transplant

See section on complications for further details.



Assessment for Transplantation

Does everyone with kidney failure get a transplant?

No. Only about 50% of patients with renal failure are on the active transplant list. Each patient will be assessed individually to see if transplantation is the best option. If you are not sure ask your renal doctor.

Reasons why kidney transplantation may not be the best treatment option:

- History of recent cancer
- Major surgery
- Bad heart, lung or blood vessel disease

If you do not wish to be on the transplant list that is your right.



How do I get on the transplant waiting list?

This will be discussed with your renal doctor who will then refer you to see the transplant surgeon.

Why do I have to see the transplant surgeon/physician?

This appointment is to assess your health and fitness to ensure you do not require any further investigations prior to your transplant operation.

What will happen at the visit?

The transplant surgeon will take this opportunity to inform you about the transplant operation and introduce you to the transplant co-ordinator. The visit to the clinic also allows you to ask any questions about kidney transplants and gives you the opportunity to visit the transplant unit / renal ward.

You may find it useful to bring along a relative or friend for support and to discuss any issues raised at your consultation. If you already have any questions that you would like to ask, it may be an idea to write them down and bring them with you on the day.

What happens next?

Your name will then be placed on the local and national transplant waiting lists and we will write to you when we have done this.



The Waiting Period

What should I do while waiting for my transplant?

- Try not to restrict your life style
- Continue to follow dietary advice
- Keep to your fluid restriction
- Take the medicines prescribed by your doctors
- Exercise
- Stop smoking
- Continue to attend your dentist regularly

All the above will help to keep you in good health for when you are called for your transplant operation. Also:

- Tell your local transplant co-ordinator/ unit if you are going on holiday so we know how to contact you.
- Inform us of any change of address/ telephone number.

Can I have a pager?

Yes. These are provided with a £10.00 refundable deposit or free of charge (depending on which unit you are from), and you have to provide the batteries. It allows greater freedom by allowing us to contact you when you are not at home. Do not give this number out to anyone.

Remember if you are at **home** and your radiopager goes off it is very likely to be an error, as we would always try to contact you by telephone first.

We request that you hand back the radiopager following your transplant, as it will be needed by another patient.

If you have a mobile phone you do not require a pager. Please give us your mobile phone number and remember when you are not at home to have it turned on at all times.

Can you tell me about the waiting time?

After you have made the decision to have a kidney transplant there will be a period of waiting until a suitable donor kidney becomes available - unfortunately we can not predict when this will be.

United Kingdom Transplant (UKT) allocates kidneys by blood group and tissue type. This system is in place to ensure the best match between you and the donor kidney and the wait can be anything from a few weeks to years. This can be a difficult time for both you and your family. Depending on your health and time on the waiting list you will be reviewed on a regular basis.

Where do donor organs come from?

There are two sources of kidneys for transplant:

- From a person who has died and the family have kindly agreed to organ donation where there are no conditions applied:

Organ donors are people who have suffered brain death, usually as a result of an injury or a brain haemorrhage. All donors are carefully screened to minimise the risk of infections such as hepatitis or HIV (AIDS) being passed on by transplant.

To protect the privacy of the donor family it is not possible to give specific details about the donor of your kidney. However if you have any anxieties or would like to talk about the general idea of organ donation please do not hesitate to ask. All the staff in the unit/ ward will be happy to answer any queries themselves or to direct you to someone who can.

- Live kidney donation (from a family member/ partner):

You will find more information about live kidney donation in Part 2 of this booklet

How do you decide who gets the kidney?

There is a scheme that is agreed across the UK on how kidneys are allocated.

- allocation managed by UK Transplant
- blood group of donor and recipient have to be compatible and are nearly always identical. (This is similar to blood matching in blood transfusions).
- The kidney must be a good tissue type match.

If two or more individuals are equally matched or in special circumstances in poorly matched pairings a points system comes into operation. This has been specially devised to maximise the success of renal transplantation while at the same time ensuring that the kidneys are allocated in the fairest way. These points take into consideration factors such as:

- age of donor and recipient
- time on waiting list
- matchability
- local donor numbers
- antibody levels



The Operation

What do I need to consider when called for my transplant operation?

- How are you going to get to hospital?
- Who is going to look after your children/pets?
- Things you need in hospital, night-clothes, wash things, and a little money for papers/ telephone.
- Lock up the house remembering to turn off all appliances.
- Inform someone where you are, pop a note through your neighbour's letterbox; you may require them to cancel your milk and papers.
- When we call you tell us if you are unwell, we require you to be in the best possible health for your transplant operation.
- You may be asked to bring your dialysis equipment e.g. Homechoice machine, as it may be required prior to the transplant. You do not need to bring fluids.
- Bring all your usual medications with you to the hospital.



Is it definite that you will have the transplant operation at this time?

No. Not until the doctor's have assessed you to ensure you are fit enough for surgery, and we do a final crossmatch test between you and the donor. In addition the surgeon will need to examine the kidney carefully to ensure there is no problem to prevent the transplant going ahead.

What do you do when you arrive at the transplant unit/renal ward?

Report to the nurses in the duty room of the transplant unit/ renal ward. You will be shown to your bed and the nurses will inform the medical staff of your arrival. You will require some final tests to ensure you are fit and to see if you require dialysis prior to surgery.

Where do you have your operation?

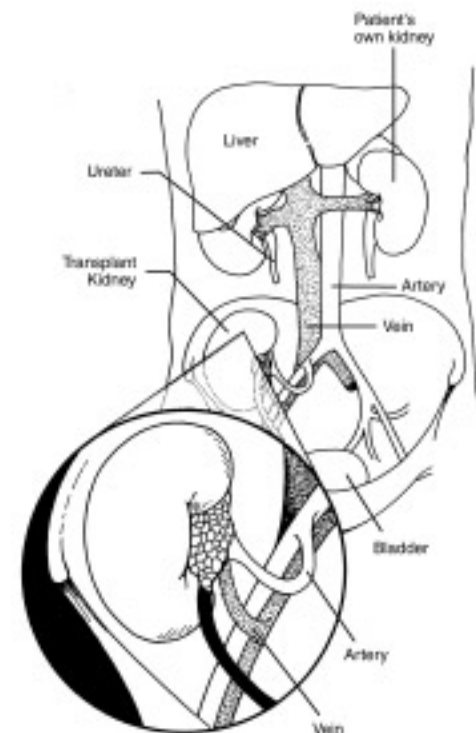
The transplant operation takes place in the operating theatre where you will have a general anaesthetic. The operation takes anything from 2-3 hours.

Where does the kidney go?

The transplanted kidney is placed in the right or left groin area. It is placed here as it is close to your bladder. The operation requires the surgeon to join up your blood vessels to those of the kidney also the urine tube (ureter) from the kidney needs to be joined to your bladder.

What happens to your own kidneys?

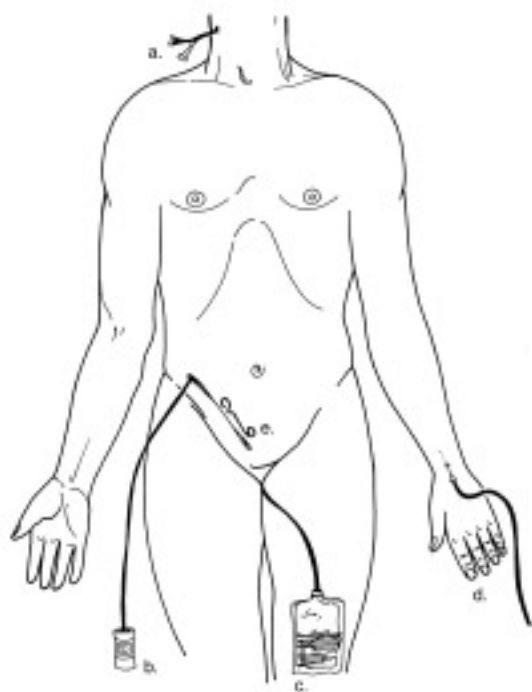
Normally your own kidneys are not removed unless there is a reason to do so. You will end up with 3 kidneys.



What tubes will I have after the operation?

- You will have a tube placed into your bladder (a urinary catheter) this is to measure the amount of urine your transplanted kidney is producing. It will be removed after about a week when the doctors are happy that your kidney is functioning well and you are drinking more fluid than you are passing.
- You may have a tube (drain) from the operation site, where your kidney has been placed. This will be removed within a few days. This is to remove any blood or fluid from the operation site to prevent any swelling or infection. Not all patients need to have a drain.
- You may have a plastic tube (a stent) placed inside the urine tube (ureter) that connects the kidney to your bladder. This prevents any kinking of the ureter after the operation. The stent requires to be removed about 3 months after your transplant operation, and will require you to come back for a day stay in hospital and a trip to the operating theatre. Not all patients need to have a stent placed. Your peritoneal catheter may be removed at the same time.

- You will have a drip line in your hand or arm and also a central line (neckline).
- You will be given control of your analgesia (painkiller). This is attached to one of your drip lines and a button control will be placed in your hand. When you press the button you will deliver a painkiller that works very quickly to prevent any further discomfort. This is called PCA - patient controlled analgesia



KEY FOR DIAGRAM
a=central line b=drain c=urinary catheter
d=drip line e=stent

Will the kidney work straight away?

After the transplant operation, the kidney may work well from the start, but it is quite possible that it will take a little time for it to work efficiently. Often the kidney reacts to the transplant process by a period of poor function - it 'goes to sleep'. During this time dialysis may need to be continued. This period of poor function should not cause alarm because in nearly every case, the kidney gradually recovers to work well, allowing dialysis to stop. If you are on peritoneal dialysis you may need a short period of haemodialysis.

The Recovery Period

Will I need dialysis after the transplant?

In most cases you will not require dialysis. A small number of patients may require to continue or start dialysis until such times as their kidney begins to function. If you are on peritoneal dialysis you may need a short period of haemodialysis.

Will I get rejection?

Rejection is a normal reaction of your body to tissue that it detects as foreign. Rejection is common and affects many patients after transplant. It affects up to 40% of patients after transplant. Rejection is usually diagnosed by a transplant biopsy. In almost all cases of rejection drugs are effective.

Will I need a transplant biopsy?

It is very common to have a transplant biopsy unless the kidney is functioning. This may help to explain why the kidney is not functioning.



What is a transplant biopsy like?

It is undertaken using ultra sound. Local anaesthetic is given at the site of the biopsy and a special needle device is used to obtain a small piece of kidney tissue. You may have had a biopsy of your own kidney. Transplant biopsy is very much more straight forward than this.

How soon can I eat after my operation?

- Immediately after your transplant operation you will not be able to eat or drink. After a few hours you should be able to start drinking sips of water and this will gradually be built up to fluids and a light diet. Within a couple of days you should be eating normally.
- Your body's requirements for energy (calories) and proteins are high after the stress of an operation. The dietitian will assess your diet on the ward and will provide advice if your appetite is poor.
- The doctor will assess how much fluid you should drink every day. Remember it is often necessary to drink much more fluid than you have been used to on dialysis - it may be many litres each day. Some people may pass large amounts of urine (polyuria) after the transplant operation. This is nothing to worry about and will eventually settle down. However, it may require you to have some of your fluids through a drip.

What about my diet when I go home?

- You should not need a special diet if your new kidney is functioning well but this is a good time to think about your general health and the positive things you can do to improve it.
- Many common health problems such as heart disease can be linked to a poor diet and lifestyle - healthy eating is an important part of keeping fit and is one of the positive things you can do to improve your health. Healthy eating is not a 'diet' - it requires a gradual change in your eating behaviour and should become a regular part of your lifestyle.
- Healthy eating involves:
 - enjoying what you eat and having a varied diet. Eating more fruit and vegetables.
 - cutting down on fat, sugar and salt
 - being a healthy weight. Limiting alcohol to below recommended weekly limits (21 units for men, 14 for women)
- The Balance of Good Health, shown on the following page, illustrates the main food groups and proportions needed to make a balanced and healthy diet:
- The dietitian will give you more information about healthy eating and food safety before you are discharged home.



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Will I gain weight after my transplant?

- Many people gain weight following a transplant, especially in the first year. This can be due to freedom from dietary restrictions, feeling well, increased appetite and lack of exercise. This is not helped by steroids which are necessary after a transplant.
- Maintaining a healthy weight is very important for your health as being overweight puts a strain on your body contributing to many health problems such as high blood pressure, heart disease and diabetes.
- If you are overweight it is worthwhile trying to lose some weight before you receive your transplant - if you wish to discuss this please ask to speak to your dietitian.
- It is possible to maintain a healthy weight after your transplant if you make the necessary changes to your diet at an early stage. Remember - it is much easier to prevent weight gain than it is to try to lose weight and it is sensible to make changes to your eating habits as early as possible to prevent weight gain.
- Advice on how to achieve and maintain a healthy weight will be tailored to your individual needs and will be discussed with the dietitian before you are discharged.

Results & Complications

How successful is kidney transplantation?

1 year graft survival - 88% (1996 - 97)

5 year graft survival - 76% (1990 - 92)

1st adult cadaveric renal transplant UK & Republic of Ireland

Figures were provide by UK Transplant. They represent the overall kidney transplant survival figures for someone receiving a first kidney. The figures for patient survival are much higher.

In general terms kidney transplantation is a very successful treatment for renal failure. However complications can occur and some of these are listed below.

Early complications can include:

Delayed Function - not all transplanted kidneys will work straight after the operation. This is not uncommon and occurs in at least 20 % of transplants. While waiting for the new kidney to start working you will probably require dialysis. Sometimes a patient treated by peritoneal dialysis can continue this treatment after transplant. More commonly haemodialysis is necessary. If you do not have a fistula a special dialysis catheter can be put into a vein in your neck at the time of your operation.

Rejection - your body will recognise that your new kidney is 'foreign' and the natural response is to attack and reject it. You will be given drugs to reduce the chance of this happening. Despite these drugs early rejection is fairly common, especially in the first three months following your transplant. The signs of rejection can be:

- Pain over your new kidney
- Fever
- Reduced urine output
- Flu like symptoms

However, in many cases there are no signs of rejection and it is detected following one of your regular blood tests. Most episodes of rejection at this stage will respond to treatment. This will require an increased dose of anti rejection drugs and/ or a change to your medication. Very rarely the rejection cannot be controlled. In these cases the kidney will need to be removed and you will have to return to dialysis. When you feel well enough you will be given the opportunity to discuss going back onto the transplant waiting list.

Infection - the anti rejection treatment that you must take following your transplant will mean that you will be more likely to develop infections. The risk is greater in the early stages after your transplant when the doses of the drugs are higher. It is important that if you think you have an infection to contact the transplant unit quickly. If you know of any friends or relatives who have a serious infection it is a good idea if you avoid visiting them while they are unwell.

Diabetes (Raised Blood Sugar) - can occur as a side effect of the anti rejection drugs. It is usually treated with a change in diet and/or tablets. Sometimes there is a need for insulin injections. (See section on drugs).

Thrombosis - is a rare complication following transplant when a clot forms in the vein or the artery of the new kidney. This means that the blood supply to the kidney will stop. If this happens you will have to go back to theatre and in most cases the kidney will have to be removed.

Urine Leak - occasionally a leak will occur where the ureter (urine drainage tube) from the transplanted kidney joins your bladder. This usually requires a return to theatre and an operation to have the leak repaired.

Bleeding - as with all major surgery there is a risk of internal bleeding. This may require a blood transfusion and a further operation to stop the bleeding.

Deep Venous Thrombosis (DVT) - following all surgery there is a risk of clots forming in the veins of the leg. This problem is less common in patients with renal disease but can still occur. Under certain circumstances these clots can be dangerous. To prevent this happening you will be given subcutaneous (under the skin) injections of heparin for the first few days following the transplant operation.

Late complications can include:

Weight gain is a common problem after successful renal transplantation because of improved appetite with better renal function, and steroid treatment. It can be minimised by eating a healthy diet (see section on diet) and by taking regular exercise.

High Blood Pressure is also extremely common following kidney transplantation because of the immunosuppressive drugs (mainly cyclosporin or tacrolimus), transplant function and pre-existing kidney disease. Many people require blood pressure lowering drugs long-term. Rarely high blood pressure can be caused by narrowing in the transplant artery.

Diabetes can develop for the first time following renal transplantation as a consequence of drug therapy (particularly tacrolimus, cyclosporin and high dose steroid treatment) in up to one sixth of patients. It is generally treated by means of a low sugar diet, but tablet treatment and sometimes insulin injections are necessary.

Cholesterol levels and other blood fats can increase after a kidney transplant, principally as a side-effect of drugs, with various other causes contributing. A healthy diet will help, though cholesterol-lowering treatment might also be required.

Cardiovascular Diseases such as angina, heart attacks, circulatory problems and strokes are all more common in transplant and dialysis patients than in people without renal disease. Receiving a kidney transplant does not reduce the risk, and it is therefore most important to stop smoking, and to follow any advice on blood pressure, cholesterol and diabetes. Keeping your weight down and taking exercise regularly are also sensible measures.

Osteoporosis and other disorders of bone are more frequently found in both men and women after renal transplantation. This is sometimes related to high doses of steroid, though a number of different factors can contribute. If you have already had a fracture or are female and post-menopausal you may be advised to have additional drug treatment such as hormone replacement. Preventative medication might also be recommended around the time of your operation.

Liver disease, mainly inflammation, can sometimes follow kidney transplant surgery as a consequence of viral infections or drug treatment. In this country it rarely causes major problems.

Recurrence of the original disease which damaged your own kidneys is a recognised complication but an unusual cause of transplant failure. Some types of renal disease are more likely to recur than others and you will be monitored closely for this problem. Occasionally a new form of nephritis can develop in a transplant kidney for reasons that are not clear.

Cancer is more common in the longer term in people with kidney transplants because of immunosuppressive treatment and types of viral infection. Two of the commonest types of tumours to develop are skin cancer and cervical cancer. Careful avoidance of sun exposure and use of powerful sun screens help reduce the risk to skin. Women should also have cervical smears performed annually. Other types of tumours such as lymphomas are seen more frequently than normal, while some types are less common.

It is clear that many of these side effects can be attributed to the immunosuppressive medication you are required to take. Unfortunately without these drugs, the kidney transplant will fail. However new drugs with fewer unwanted effects are continually under development and your therapy might change in the future if these become widely available and accepted.

What is rejection?

Normally the body is protected against “foreign” material, such as bacteria and viruses, by the immune system recognising the foreign material and attempting to damage it. Unfortunately it does exactly the same to a kidney transplant and this is called **Rejection**. Immunosuppressant drugs attempt to stop or reduce this response of the immune system. **Acute Rejection** is relatively common and may occur at any time after a kidney transplant but is more likely early after the transplant. During acute rejection patients may feel unwell, feverish, have pain over the transplant or notice a reduction in urinary output. However, patients may feel perfectly well and rejection is only diagnosed because of a worsening of kidney function blood tests. Acute rejection is normally confirmed by doing a biopsy of the transplant kidney. It can usually be treated by giving additional steroids for a few days but it does need to be diagnosed and treated promptly. Your usually immunosuppressant drugs are sometimes changed after an episode of acute rejection. **Chronic Rejection** is a much slower process and occurs over months or years with a slow worsening of kidney function tests. It is also relatively common but no specific treatment has yet been shown to stop this form of rejection.

Is infection more common after a transplant?

The operation itself and your immunosuppressant drugs make you more susceptible to infections. The majority of these infections, such as wound, urinary and chest infections are caused by relatively common bacteria which are usually easily treated with relatively common antibiotics. However, because of your immunosuppressant drugs you are also susceptible to serious and occasionally life-threatening diseases from rarer infections such as cytomegalic virus, fungal infections and pneumocystis carinii. Cytomegalic Virus Disease (CMV) deserves special mention. In patients who are not immunosuppressed by drugs or an illness, CMV is usually a very mild viral illness. However, in patients on immunosuppressant drugs it may be much more serious and may be life-threatening. Patients may feel vaguely unwell, feverish or breathless. Patients at greatest risk of developing serious Cytomegalic Virus Disease (CMV) are those who have never had CMV before but receive a kidney from a donor who has had CMV. However, with present drug regimens serious infection with these organisms can usually be prevented (you may be on additional drugs for this) or if they do occur can nearly always be treated. With time the increased risk of infection because of immunosuppressants lessens but never goes away completely.



Medications

How are my tablets going to change?

Some medications will be stopped. Some of the medications you are taking are needed because your kidney is not working properly. After a transplant, these medicines will be stopped. They include phosphate binders, alfacalcidol, anti-itch tablets, iron supplements and erythropoietin.

Some medications will be started. The most important new tablets you will be started on are called IMMUNOSUPPRESSANTS. The immune system is our body's natural defence mechanism. It is programmed to recognise and destroy anything unfamiliar. This includes a transplanted kidney as well as the organisms that cause infection.

After a kidney transplant, you will be prescribed immunosuppressants to prevent the immune system from rejecting the new kidney. You **must** take them every day while your kidney transplant is functioning.

What immunosuppressants will I take?

Initially you will be on a combination of three of the following medicines:

1. Tacrolimus (Prograf)
2. Cyclosporin (Neoral)
3. Prednisolone
4. Azathioprine (Imuran)
5. Mycophenolate Mofetil (Cellcept)

If you do not take these medications as prescribed, it will result in rejection and the loss of your new kidney.

These drugs need to be finely tuned as too little may lead to rejection and too much may lead to infection. Early after the transplant the need for immunosuppression is high but this need lessens with time, so these drugs will be slowly reduced by your doctors.

There are a number of new drugs soon to be available and you may be prescribed one of those when you have your transplant operation. One such drug is called Sirolimus (Rapamycin).

Two further drugs which are licenced for renal transplantation are Basiliximab (Simulect) and Daclizumab (Zenopax). These drugs (known as monoclonal antibodies) are sometimes given in the early period after a transplant. Only two or five doses are given by vein via a drip or infusion. These new drugs may allow us to use less of other medications and recent trials suggest that they have very few, if any, side effects.

What are the possible side effects?

Immunosuppressants, like most medicines, can have some unwanted side effects. However, just because a medicine has the potential to cause adverse effects, it does not necessarily mean you will get them. All anti-rejection drugs will increase your risk of infection. The risk lessens as they are cut down, but common-sense precautions will be necessary. Any signs of serious infection will need to be brought to the attention of the transplant unit/ renal ward immediately.

The individual immunosuppressives may have their own side effects as follows:

Tacrolimus - shaking of the hands, headaches, impaired vision, 'pins and needles', raised blood sugar levels (diabetes). Kidney damage at high blood levels.

Cyclosporin - high blood pressure, increased or unusual hair growth, tender or swollen gums, shaking of the hands, raised blood sugar levels (diabetes) and kidney damage at high blood levels.

Prednisolone - irritation of the gut lining, indigestion, increase in appetite, weight gain, rounded face, thinning skin & bones and raised blood sugar levels (diabetes).

Azathioprine - unusual but can cause an upset in liver function and white blood cells in the blood.

Mycophenolate Mofetil - diarrhoea, bloating, heartburn, nausea and vomiting. Inform the doctors if you experience side effects - they may want to cut down the dose or give you an alternative.

What other medications do I have to take?

You may be asked to take the following :

- co-trimoxazole - an antibiotic to reduce the risk of bacterial infection
- ranitidine - to protect the stomach against ulcers and heartburn
- antiviral medications such as aciclovir, ganciclovir or valaciclovir
- amphotericin lozenges - to prevent oral fungal infections
- heparin - for the 1st weeks after transplant heparin may be given - to prevent blood clots

Can I take any other medicines?

Some of these medicines are affected by and do themselves affect other medicines. Please discuss your current medication with the pharmacist if you need to buy 'over the counter' medicines for minor ailments.

Your GP may wish to contact the transplant unit/ renal ward before giving you any new prescription medicines.

If you have any concerns about any aspect of your medicines, please do not hesitate to ask.

If you are taking either cyclosporin or tacrolimus the following drugs may interact. Your renal/ transplant doctor should be informed before these drugs are used.

For example:

- erythromycin
- clarithromycin
- fluconazole
- ketoconazole
- St. johns wort
- herbal medicines
- grapefruit juice

Many other drugs also interact. If you or your doctor are unsure please discuss with your renal/ transplant doctor.

Herbal medicines

It is suggested that you do not take any herbal medicines (in particular St. johns wort should not be used) without first checking with your renal/ transplant doctor.

Grapefruit juice

Grapefruit juice taken alone with cyclosporin or tacrolimus can alter the levels of these drugs in your blood. It is probably best to avoid grapefruit juice. For further advice speak to your renal/ transplant doctor.

Will I be asked to take part in any clinical research trials?

The field of transplantation is constantly improving. You may be asked to take part in clinical research trials. Any trial will be discussed with you in full. If you decide not to take part in any trial your treatment will not be affected in any way.

Living with a Transplant



Going home what can I expect?

Follow up - You require to be seen regularly in the out - patient clinic following your discharge home from hospital. The time between appointments increases depending on how well you are. At these appointments you will have your bloods monitored and be seen by one of the renal /transplant follow-up staff. Do not take your morning cyclosporin / tacrolimus tablets on the morning of your clinic visit until after your blood test and then it should be taken as normal.

If we require to make any changes to your medications/ treatment we will contact you by phone or speak with/ write to your GP. In some cases we may require you to come into hospital.

In addition to your clinic appointments you may require to attend the transplant unit/ renal ward on a regular basis for blood tests in the first weeks following your discharge from hospital.

Returning to work - Our aim is to allow each transplant patient to return to an independent lifestyle with a good quality of life. Most transplant recipients remain off work for 2-3 months, but this depends on the individual patient and their occupation. Please discuss when you can return to work with the surgeon or physician caring for you.

Driving - Usually you are able to drive at about 6 weeks following your operation. You should also check with your individual insurance company. At that time inform your insurance company and the DVLA that you have had a transplant operation. Remember always to use your seat belt.

Equipment - If your transplant is successful you should have no further use of your dialysis equipment. Contact your local peritoneal dialysis sister to arrange for this equipment to be uplifted and for further deliveries to be cancelled.

Family Planning - Female It is not advisable to consider pregnancy within the 1st year post transplantation. Transplant patients of child-bearing age should practice birth control following transplantation. Should you wish to take the oral contraceptive pill, discuss this at your out-patient appointment. **Male** - It is important that our male patients take 'pregnancy advice' re fathering a child. We do not advise that you father a child whilst taking certain medications. It may require us to change your medications to reduce the risk.

Libido - Some patients have a change in their libido. This is not uncommon and it may take some time for your sex drive to return to normal. If matters don't improve please discuss this with a member of the medical staff at your out-patient appointment.

Sex - You can resume sexual activity once you feel well enough. However you may find that your sex drive is reduced during the early convalescence period, although this will gradually return to normal.

Impotence - Some patients may experience/ continue to experience impotence. This is not uncommon and may in some cases be easily treated. Please discuss any problems you maybe experiencing with the medical staff at your outpatient appointment.

Pregnancy - It is not advisable to consider pregnancy within the 1st year post transplantation and it is essential that you use some form of contraception. After the first year if you wish to consider having a baby you require to contact the medical staff at the clinic for advice. Many women who have had a successful transplant operation enjoy a normal pregnancy, however you may need to have some of your drugs changed during your pregnancy and also if you want to breast - feed your baby.

Infertility - Some patients may experience difficulty in conceiving/ fathering a child. Please bring this to the attention of the medical staff. It is not uncommon and we can refer you for expert help.

Breast checks - This should be performed at least monthly and it is best to undertake these tests at a different time from your period. If you are unsure how to perform these tests our medical staff will instruct you. We also have leaflets available. When you examine your breasts you are checking for any swelling, lumps, skin breakdown and discharge from the nipple remembering to check under your arm as well. Please inform your GP if you discover any of the above or the clinic medical staff.

Smears - as with all women who are sexually active it is important to have a regular smear test. In post transplant patients we recommend that this is performed yearly as you are taking immunosuppressant medications.

Testicular checks - All men should check at least monthly for any swelling or lumps. If you do not know how to examine yourself please ask a member of the medical staff who will advise you or we have leaflets available.

Travel - There is no reason to prevent you from travelling within the UK when you feel well enough but you should contact one of the medical staff you see regularly in the transplant follow-up clinic for advice. If you are planning to go overseas - we do not recommend this in the first 6 months post transplantation. Before booking any overseas holidays always check that you are fit for travel by asking one of the medical staff in the outpatient clinic. If you are going away you should always take this booklet and sufficient medication with you for your holiday. It is usually a good idea to obtain prescription supplies well in advance so as never to be short of medication. Transplant medications make you more susceptible to skin cancer, so sunscreens and hats should be worn during periods of sun exposure. You will also need to get advice from the transplant unit/ ward on **vaccinations** and **antimalarials** well before holidays or travel abroad. As you are taking immunosuppressants it is important that you do not have certain vaccines, called **live vaccines**, as this is likely to give you the disease the vaccine is designed

to protect you against. It is also important that you avoid close contact with anyone who has recently been given a live vaccine. Other vaccines, called **inactivated vaccines** are not dangerous to receive, but might not give you full protection.

Alcohol - It is possible to take alcohol within the limits of the National guidelines:

men - 21 units per week

women - 14 units per week

1 glass of wine = 1 unit

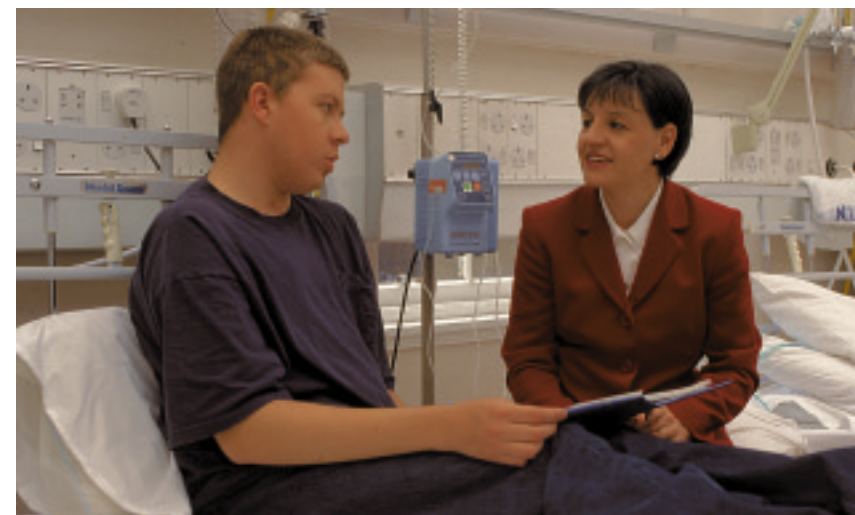
½ pint of beer = 1 unit

Social worker

We appreciate that coming into hospital can be as stressful for both patients and their families for a whole variety of reasons. A social worker is available in the transplant unit/ renal ward to assist and support you throughout your stay and following your discharge.

They can offer psycho-social support and advice, on a whole range of matters, and will be happy to meet with you, if you so wish. You may already have met with them during your spell on dialysis.

Some of the questions asked relate to Welfare Benefits and a few general guidelines are listed. If you are in doubt you should contact your local Benefits Office or speak with one of the social workers.



What benefits am I entitled to?

Fares - If you are in receipt of Income Support, Family Credit, hold an HC2 (Low Income Certificate), Disabled Workers Allowance or Job Seekers (Income based) Allowance, you will be able to claim fares for your trips to hospital. You should ask the ward or clinic staff for a Certificate of Attendance and take this to the hospital cashier, along with proof of benefit, to reclaim your fares.

Unfortunately, fares are not paid for those visiting you. If however they are in receipt of Income Support, they should approach their local Benefits Agency and request a grant or loan from the Social Fund. If your relatives are finding it financially difficult to visit you, have a word with one of the social workers and it may be possible to get a small grant from one of the hospital or kidney charities.

Income Support - If you are in receipt of Income Support, you should advise your local Benefits Office of your admission to hospital. Your benefit will continue for 6 weeks before being reduced.

DLA (Care Component) & Attendance Allowance - These benefits will cease after 4 weeks in hospital. You should, once again, advise your local Benefits Office of your admission.

SDA, ICB, IVB, SB and most other pensions are reduced after 6 weeks. Once again, you should advise your local Benefits Office. If you are in any doubt about your eligibility for any of these benefits, you should contact your local Benefits Office, and you must advise them that you have been transplanted, and as such your situation has changed.

Prescriptions - During the time you have been on dialysis, you will have received free prescriptions, either direct from the hospital or from your GP. Unfortunately, now you are transplanted, you are eligible to pay for these drugs.

Most patients find it beneficial to purchase a pre-paid certificate from their local Health Board for 1 year. Applications for this are available from your pharmacist or from the post office.

Over the past few years, the demands on the charities we use have increased, and they are not always able to give as much help as they would wish. If, however, you have problems purchasing your drugs, please do not hesitate to contact the social workers, and they will do their best to help.

Once you are discharged from the unit/ renal ward, social workers are still available to offer advice and support to yourself and your family.

Part 2

Live kidney donation

This information has been written to give a basic introduction to those considering donating a kidney to a relative with kidney failure. Further information can be obtained from the doctor at your renal unit or from the transplant co-ordinators.

Who can donate a kidney?

Mostly it is a close relative such as a parent, sister or brother, or a spouse/partner who is considered. Occasionally an aunt, uncle or grandparent has been suitable. Close relatives need to be linked genetically, but in cases where the donor is unrelated such as a spouse, an additional report is submitted to the Unrelated Live Transplant Regulatory Authority (ULTRA). In all cases donor and recipient require to have a compatible blood group. Family members may have different blood groups, so that it may not be possible for one person to give another a kidney even when they are within the same family.



Can I manage on one kidney?

Before a kidney is removed from the donor we check very carefully that the blood supply to the kidneys and the way they work is normal by performing several blood tests and special x-rays. One of the blood tests performed checks for viral infections. The general health of the donor must also be very good and a thorough medical examination will be organised and repeated on a number of occasions. Because of all these tests we can be sure that potential donors have two perfectly normal kidneys and can afford to give one away.

Some people are born with only one kidney, others lose a kidney in an accident and live a normal life, so, yes, you can manage with one kidney.

Are there any long term problems from giving away one kidney?

Large studies have been performed which have checked people who have given one kidney to a family member. There does not appear to be any risk of serious problems from having given this gift. There is a slight increased risk of problems of mildly raised blood pressure, but this may be because the patients come from a family where kidney disease has been detected. Therefore there do not seem to be any serious long term problems from giving away one kidney.

What happens if all my tests are okay?

Providing your general health is found to be good and your kidney is suitable to donate to your relative, a date will be made for the proposed operation. This date can be planned to allow organisation of work and domestic commitments. The recipient usually comes into hospital two days before the operation and the donor one day before the planned transplant. A number of final tests are performed to make sure that the transplant operation can go ahead.

Do I get paid while off work?

This depends on the individual's employer. They are not obliged to pay you sick pay while you are off work. We advise that you speak to your employer in the early stages of the live donor process. Most employers are understanding so it is not a problem. If this is not the case then it may be possible to claim social security benefits at this time.

Does it hurt and how long will I be in hospital?

Donating a kidney is not a small operation and there can be discomfort afterwards. The operation takes about 2 hours after which a special infusion of pain killer is given and this reduces the pain considerably. Most donors are up and around after a few days and are ready for discharge from the hospital approximately 7 days after the operation.

Any patient who has a general anaesthetic runs a risk, but all the tests that are done before the operation try to ensure that every risk is made as small as possible.

It is very important that after discharge there is a period of rest before returning to work. However, depending on the type of employment, most donors return to work after approximately 4 weeks.

Is there a risk of the transplant not being successful?

Yes, unfortunately we cannot guarantee a 100% success. This type of transplant is more successful than those performed after someone has been declared brain stem dead and their organs are used for transplant. Of course there can be problems: poor blood supply to the kidney or severe rejection can cause failure of the transplant with great disappointment to everyone. We encourage families to talk about this possibility, even though it is rare, so that any worries are discussed before going ahead with the operation. However, transplants within families are very successful and we estimate that over 90% of live donor kidney transplants are still working well at 1 year. Many of our patients who are fit and well more than 20 years after their transplant had a kidney from a live donor.

Can I talk to someone who has been a live related donor?

Yes, contact the transplant co-ordinators who can arrange for you to speak to someone who has personal experience of this procedure.

Do I need to be followed up afterwards?

An appointment for the surgical follow up clinic is made for six weeks after discharge to check that the wound has healed and that you are fully recovered. You will then attend a follow-up clinic to have your blood pressure and kidney function checked on an annual basis.

Some donors feel a sense of anti-climax after the operation as all the excitement subsides and attention is given to the person who has received the kidney rather than the one who has given it. However it is undoubtedly true that your gesture is never forgotten.

This is only an introduction to live kidney donation. Please contact the transplant co-ordinator should you wish more written information or to discuss the matter further.

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