CONTENTS

INTRODUCTION

Welcome to the Kidney Transplant Unit at the Royal Infirmary of 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, over 1,000 patients have experienced the benefits of kidney transplantation in the Edinburgh Kidney Transplant Unit.

This booklet provides information for patients waiting for 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 Transplant Unit long before a transplant is performed, so that they may ask any questions or tell us of any worries that they may have.

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

Useful contact numbers:

RIE switchboard: 0131 536 1000

Ward 206 Transplant Unit: 0131 242 2068/9 (patient enquiries / out of hours contact number)

Ward 215 Transplant and Renal High Dependency Unit: 0131 242 2153

Renal Social Workers: 0131 242 7850

Transplant Co-ordinator Secretary: 0131 242 1635

The Kidney Transplant Unit Staff (Royal Infirmary of Edinburgh)

Clinical Director: Mr James Powell

Consultant Surgeons

Ms Anya Adair
Mr Murat Akyol
Mr John Casey
Mr Ian Currie
Ms Lorna Marson
Mr Gabriel Oniscu
Mr Andrew Sutherland
Mr John Terrace
Ms Sonia Wakelin

Consultant Physicians

Dr Bean Dhaun
Dr Paddy Gibson
Dr Lorna Henderson
Dr David Kluth
Dr Wendy Metcalfe
Dr Paul Phelan
Dr Michaela Petrie
Prof Neil Turner
Dr Caroline Whitworth

Live Donor Co-ordinators 0131 242 1703

Ms Kath Brown
Mrs Nina Kunkel
Ms Jen Lumsdaine
Mrs Sarah Lundie
Ms Lynne McCutcheon

Kidney Transplant Co-ordinators

Miss Alison Glover	0131 242 1727
Miss Debbie Mills	0131 242 1705
Mrs Laura Pairman	0131 242 1728

Pancreas and Islet Co-ordinators

Mrs Kirsty Duncan	0131 242 1730
Mrs Christine Jansen	0131 242 1704
Mrs Melanie Phillips	0131 242 2894

Senior Nursing Staff

C/N Lynne Beveridge
C/N Wendy King
C/N Steven South-Jones

Clinical Pharmacist

Carol Dolderson

Physiotherapist

Aubrey McCallum

Where are the Outpatient Clinics?

The transplant assessment and follow-up clinics are held in Outpatients Department 1, Royal Infirmary of Edinburgh (OPD1 RIE). This clinic is located on the ground floor and can be accessed via the main entrance to the hospital.

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 hospital entrances are locked from 9pm to 6am. There are buzzers at the entrances where the security staff will give you access to the hospital. If you are carrying dialysis equipment, we suggest you enter via the Emergency Department (A&E), as a porter can be called to help you.

You will be asked:

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

How to get to the hospital

By car

The Royal Infirmary of Edinburgh is on Old Dalkeith Road (A7) on the south side of Edinburgh. The postcode for the hospital is EH16 4SA.

Directions from City Centre:

Leave the city centre on North Bridge at the east end of Princes Street. Follow this road, taking the first exit (left) at the roundabout with Liberton Road and Lady Road. Go straight over the Lady Road roundabout and take the third exit (right) off Cameron Toll roundabout on to Old Dalkeith Road (A7). Turn left into the hospital after three-quarters of a mile.

Directions from bypass:
Leave the Edinburgh City Bypass (A720) at the Sheriffhall roundabout on to Old Dalkeith Road (A7) toward Edinburgh City Centre. Turn right into the hospital after just over 2 miles.

Entry to the site is via two access roads, one to the north and one to the south of the site. There are free disabled parking spaces located near the main entrances.

Car parking:
Improvement works to car parking and traffic management are taking place on the Royal Infirmary of Edinburgh site, as part of work on the new hospital for children and young people being built next to the RIE. The new £150 million building will replace the Royal Hospital for Sick Children and will also be home to the Department of Clinical Neurosciences (currently based at the Western General Hospital) and Child and Adolescent Mental Health Services (CAMHS).

Construction began in February 2015 and the building is scheduled to open to patients in the spring of 2018. For more information on car parks at the RIE, please see our website: **www.nhslothian.scot.nhs.uk/GoingToHospital/Locations/RHSCDCNRIECampusWorks/RIECampus**

Do I have to pay to park at the hospital?
NHS Lothian does not own or operate the car parks at the Royal Infirmary of Edinburgh. The car parks are managed by an external company, Consort Healthcare, who also set the charges.

However, we understand that, for some people, the car parking fees may be expensive and, also, that you may have travelled from some distance to the hospital. When a patient is called in for transplant, the transplant staff have guidelines on issuing passes, which will allow parking at a reduced fee. Please discuss this with the nurse in charge of the unit at this time.

For details of car parking charges for patients and visitors: copy the following link: **www.nhslothian.scot.nhs.uk/GoingToHospital/Locations/RHSCDCNRIECampusWorks/RIECampus**

Please note that lost tickets are charged at the full daily rate.

By bus
There are many buses that serve the Royal Infirmary of Edinburgh:

Edinburgh
www.lothianbuses.com
0131 554 4494

Edinburgh and Central Scotland
www.firstgroup.com/journey-planner

West Lothian
www.horsburghcoaches.com

Borders
www.munrosofjedburgh.co.uk
Traveline: 0871 2002233

Walking / cycling
A new cycle/bus lane from Cameron Toll to the Royal Infirmary of Edinburgh via Old Dalkeith Road, as well as improvements to the cycle and footpaths on Craigmillar Castle Road, may make cycling or walking an option for some patients and visitors.

There is currently provision to park both bicycles and motorbikes on site, free of charge. Motorcycle parking is within marked spaces outwith the car parks at various points around the perimeter of the building. Cycle parking is available close to all the entrances to the building, in the form of Sheffield stands. CCTV monitors these areas at all times.

For more details of cycling routes/maps, see the Spokes (the Lothian Cycle Network) website at **www.spokes.org.uk/spokes-maps/**

Who will I meet?

Some of those responsible for your care include:

Doctors: a team of surgeons, physicians, anaesthetists and radiologists will look after you. You may already know some of them from outpatient clinics or previous hospital admissions. As the Royal Infirmary of Edinburgh is a teaching hospital, you will also see doctors in training, as well as senior doctors and 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.

Transplant Co-ordinators: you may 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.

Chaplain: the RIE 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.

Assessment for transplantation

The first step in being considered for transplant is to talk to your renal physician, who will refer you for assessment if appropriate.

What are the benefits of kidney transplantation?

Kidney transplantation is an excellent treatment for kidney failure and 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)

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.

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

- History of recent cancer
- Major surgery
- Bad heart, lung or blood vessel disease
- You may choose not to have a transplant

Why do I have to see the transplant surgeon?

This appointment is to assess your health and fitness to ensure you do not require any further investigations before a decision is made regarding putting you on a waiting list for transplant.

What will happen at the visit?

The transplant surgeon will take this opportunity to talk to you about the transplant operation and introduce you to the transplant co-ordinator. There will be a discussion with you about your general health. The transplant surgeon will decide if you need to have any tests before going on to the transplant list. The visit to the clinic also allows you to ask any questions about kidney transplants, so that you can decide whether a kidney transplant is the right thing for you.

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.

THE WAITING PERIOD

What should I do while waiting for my transplant?

- Stop smoking
- Continue to follow dietary advice
- Keep to your fluid restriction
- Take the medicines prescribed by your doctors
- Exercise
- Try not to restrict your lifestyle
- Continue to attend your dentist regularly
- Keep up-to-date with smear tests, mammograms and bowel screening
- Maintain a steady weight – if you are overweight, further weight gain may stop you from having a transplant

All of the above will help to keep you in good health for when you are called for your transplant operation. Also, tell your transplant co-ordinator if you are:

- Going on holiday, as they may need to suspend you from the list while you are away
- Changing address/ telephone number
- Unwell or need an operation

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 cannot predict how long this will be.

If, at any time, you are unwell or in hospital, it is likely that you will be temporarily suspended from this list. If you would like more information about this, please contact your renal physician.

Organ Donation and Transplantation (ODT) 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 average waiting time is two and a half to three years. This can be a difficult time for both you and your family. You will be reviewed on a regular basis while you are on the Transplant List.

Where do donor organs come from?

There are two sources of kidneys for transplant:

1. From a living donor: a transplant from a living donor is often the best option and provides an excellent long term outcome. Nowadays, it does not need to be a close family member who donates. Anyone wishing more information about becoming a living donor should contact their local unit.
   Visit **www.livingdonationscotland.org** for further details.

2. From a person who has died and the family have agreed to organ donation: either people who have suffered brain death, known as Donation after Brain Death (DBD) or Donation after Circulatory Death (DCD) from patients who are declared dead following absence of breathing or heartbeat. The organs are retrieved rapidly following this type of donation.

Can I have any information about my donor?

It is possible to find out some details about the donor of your kidney and write a letter to the donor family. Your transplant co-ordinator will discuss this with you at an appropriate time after the transplant has taken place.

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

The field of transplantation is constantly evolving. 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.

THE OPERATION

What do you need to consider when called for a kidney transplant?

- How are you going to get to hospital?
- Who is going to look after your children/pets?
- Things you need in hospital: nightclothes, wash things and a little money
- Lock up the house, remembering to turn off all appliances
- Tell someone where you are: pop a note through your neighbour's letterbox; you may need them to cancel your milk and papers
- When we call you, tell us if you are unwell. You need 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 needed before the transplant. You do not need to bring fluids
- Bring all your usual medications with you to the hospital

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

No. The doctors must assess you to ensure that you are fit enough for surgery. We may also need to do a final compatibility 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. In some instances, the donation may not proceed.

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

Report to the nurses in the Transplant Unit / Renal Ward. You will be shown to your bed and the nurses will tell the medical staff that you have arrived. We will do some final tests to ensure you are fit and to see if you require dialysis before surgery.

Where do I have my operation?

The transplant operation takes place in the operating theatre where you will have a general anaesthetic. The operation takes between 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 my own kidneys?

Your own kidneys are not normally removed unless there is a reason to do so.

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 five days, 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 take away any blood or fluid from the operation site to prevent any swelling or infection. Not all patients need to have a drain.

You will 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 needs to be removed about six to eight weeks after your transplant operation, so you will need to come back for a day stay in hospital and a trip to the operating theatre. Your peritoneal catheter, if you have one, 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 reduce any further discomfort. This is called PCA - Patient Controlled Analgesia.

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, especially if the kidney comes from a donor who has donated after circulatory death. 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?

A number of patients may have to continue or start dialysis until their kidney begins to function.

Will I get rejection?

Rejection is a normal reaction of your body to tissue that it detects as foreign. Rejection is common and affects up to 20% of patients after transplant. In almost all cases of rejection, drugs are effective at treating it.

Will I need a transplant biopsy?

It is very common to have a transplant biopsy. This may help to explain why the kidney is not functioning. The biopsy is done using ultrasound. 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. A transplant biopsy is very much more straightforward than this.

How soon can I eat after my operation?

You should be able to eat and drink soon after the transplant operation.

Your body’s requirements for energy (calories) and proteins are high after the stress of an operation. The dietitian may assess your diet on the ward and will provide advice if your appetite is inadequate.

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, you may need to have some of your fluids through a drip at this time.

How soon will I be up and around after my operation?

A physiotherapist will help you make as full a recovery as possible after your operation. The physiotherapist’s role is to teach you a range of simple exercises that will help you avoid the complications that can occur following surgery, e.g. the risk of chest infection can be reduced by regular deep breathing and coughing exercises.

It is also important that you start gentle mobilisation in the first few days after your operation. This has many benefits and, again, will

help to minimise the risks associated with surgery.
The physiotherapist and nursing staff will assist you with this.

The physiotherapist will continue to see you for a few days after your operation to ensure your lungs are clear and that you are up and about without any issues. Before you go home, it is also useful to discuss safe progression of exercise and the re-introduction of any hobbies in the longer term.

RESULTS AND COMPLICATIONS

How successful is kidney transplantation?

1-year DBD transplant survival - 94% (2011 - 2014)
1-year DCD transplant survival - 94% (2011 - 2014)

5-year DBD transplant survival - 87% (2008 -2010)
5-year DCD transplant survival - 86% (2008 - 2010)

10-year DBD transplant survival - 74% (2002 - 2004)
10-year DCD transplant survival - 77% (2002 - 2004)

1st adult cadaveric kidney transplant UK.
Figures provided by NHS Blood and Transplant, Organ Donation and Transplantation.

All organ donors are assessed to find out if they have any infection or illness that could be passed to potential transplant recipients. Every possible precaution is taken to prevent the transmission of infections, cancer or any other potentially life-threatening condition to patients who receive an organ for transplantation. Whilst every effort is made to gather this information, we are unable to give a 100% guarantee that the organ that you will receive is completely free of risk factors.

We are very careful in assessing the function of the donor organ before transplant. Due to the shortage of organ donors, we now consider some people to be potential donors who we would not have accepted as donors a few years ago. This means you could receive an organ from an older donor or that the organ to be transplanted is not functioning perfectly. The results of transplants from donors like these are still seen to be very acceptable. Therefore, it is felt that the balance of risk is in favour of going ahead with such a transplant rather than leaving a patient waiting on the list.

If there are any special risk factors associated with a donor over and above those described, they would be discussed with you immediately before any transplant procedure.

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 40% 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.

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.

In most 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 on to the transplant waiting list.

Infection: the anti-rejection treatment that you must take following your transplant means 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 you contact the Transplant Unit quickly if you think you have an infection. 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.

The majority of the infections that occur, such as wound, urinary and chest infections, are caused by relatively common bacteria, which are usually easily treated with common antibiotics. However, because of your immuno-suppressant drugs, you are also susceptible to serious and occasionally life-threatening diseases from rarer infections such as Cytomegalovirus (CMV), fungal infections and pneumocystis jirovecii.

CMV disease deserves special mention. In patients who are not immuno-suppressed by drugs or an illness, CMV is usually a very mild viral illness. However, in patients on immuno-suppressant 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 CMV disease 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 immuno-suppressants lessens but never goes away completely.

Your blood will also be screened regularly for polyoma virus after your transplant . The treatment for this is for your immuno-suppression to be decreased.

Thrombosis: this 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 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:

Weight gain is a common problem after successful kidney 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 extremely common following kidney transplantation because of the immuno-suppressive drugs 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 is common in the first year following kidney transplantation as a consequence of drug therapy and excessive weight in up to one in four 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, so it is 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 bone disorders are more often found in both men and women after kidney 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.

Recurrence of the original disease that 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 immuno-suppressive treatment. The commonest type of tumour to develop is skin cancer. Careful avoidance of sun exposure and use of powerful sunscreens help reduce the risk to skin. 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 immuno-suppressive medication you are required to take. Unfortunately, without these drugs, the kidney transplant will fail. However, new drugs with fewer unwanted side-effects are continually being developed and your therapy might change in the future if these become widely available and accepted.

Chronic rejection is a slow process and occurs over months or years, with a gradual worsening of kidney function tests. It is also relatively common, but no specific treatment has yet been shown to stop this form of rejection.

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

MEDICATIONS

How are my tablets going to change?

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

Some medications will be started. The most important new tablets you will be started on are called immuno-suppressants. 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 immuno-suppressants to prevent the immune system from rejecting the new kidney. You must take them every day while your kidney transplant is functioning.

What immuno-suppressants will I take?

You are likely to be on one or more of the following medicines:

1. Tacrolimus (Prograf or Advagraf)
2. Prednisolone
3. Mycophenolate Mofetil (Cellcept or Myphenax)/Mycophenolate Sodium (Myfortic)
4. Sirolimus.

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 immuno-suppression is high, but this need lessens with time, so these drugs will be slowly reduced by your doctors.

What are the possible side-effects?

Immuno-suppressants, 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 immuno-suppressives may have their own side-effects, as follows:

Tacrolimus: shaking of the hands, headaches, impaired vision, ‘pins and needles’ and raised blood sugar levels (diabetes). Kidney damage is possible at high blood levels (which is why coming to clinic and getting your bloods checked is so important).

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

Mycophenolate Mofetil (MMF): diarrhoea, bloating, heartburn, nausea and vomiting.

Mycophenolate sodium: side-effects are similar to those detailed above for mycophenolate mofetil.

Sirolimus: raised cholesterol and triglycerides, decreased white blood cells, anaemia, irritation of, or sores, in the mouth and delayed wound healing.

Tell the doctors if you experience side-effects, as 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 valganciclovir
- heparin: to prevent blood clots (for the first few days after the operation).

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 in the Transplant Unit.

The programme 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 will 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.

Can I take any other medicines?

Your immuno-suppression may interact with 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.

Herbal medicines

You must not take any herbal medicines without first checking with your renal/transplant doctor.

Grapefruit juice

It is best to avoid grapefruit juice as it can interact with your immuno-suppression and cause high blood levels of the immuno-suppressive drug.

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 (14 units for both men and women)

The transplant co-ordinator will give you more information about healthy eating and food safety before you are discharged home.

Food safety

As a result of taking immuno-suppression, you have an increased risk of picking up an infection, which could be food related. It is important to follow the advice that you will be given on discharge to minimise this risk, especially during the immediate few months after your operation.

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. 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.

Follow-up

You will need to be seen regularly in the outpatient 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 tacrolimus tablets on the morning of your clinic visit until after your blood test. Then it should be taken as normal.

If we need 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 ask you to come into hospital.

Returning to work

The aim of a transplant is to allow each recipient to return to an independent lifestyle with a good quality of life. You should expect to 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 six weeks following your operation. You should also check with your individual insurance company. 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 community dialysis team to arrange for this equipment to be uplifted and for future deliveries to be cancelled.

Family planning, pregnancy and sexual health

Some patients may experience difficulty in conceiving/ fathering a child. However, fertility can rapidly return post transplant.

Females: it is not advisable to consider pregnancy within the first year after your transplant and it is essential that you use two forms of contraception. After the first year, if you wish to consider having a baby, you should contact the medical staff at the clinic for advice. Many women who have had a successful transplant operation enjoy a normal pregnancy, however you will need to have some of your drugs changed during your pregnancy and also if you want to breastfeed your baby.

Males: we do not advise that you father a child whilst taking valganciclovir and MMF, both of which may be associated with birth defects. It is therefore important to use condoms if you are having sex.

Libido and Impotence: 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. This usually gradually returns to normal, though some patients will have a change in their libido. Some men will experience impotence. This is not uncommon and may in some cases be easily treated.

Please discuss any concerns with a member of the medical staff at your outpatient appointment.

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 for lumps as well. Please inform your GP or renal physician if you discover any of the above.

Mammograms: all women aged between 50 and 70 years old are offered mammograms every three years and it is important that you attend for these.

Smear tests: as with all women who are sexually active, it is important to have a smear test every three years. In Scotland, smear tests are offered to women aged 20 to 60 years old.

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, sun exposure and vaccinations

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. We do not recommend overseas travel in the first six months after your transplant operation.

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 and this risk increases with time. For instance, 20 years after transplantation, more than half of all transplant patients will have had a skin cancer. Whilst all transplant patients are at risk, some are more likely than others to develop skin cancer. It is important that you read the skin cancer information leaflet that you will be given on discharge. Sunscreens and hats should be worn during periods of sun exposure.

You will also need to get advice from your GP on vaccinations and antimalarials well before holidays or travel abroad. As you are taking immuno-suppressants, 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.

Other vaccines, called inactivated vaccines, are not dangerous to receive, but might not give you full protection. We recommend that you receive the flu vaccination and pneumococcal vaccination.

Alcohol

It is possible to drink alcohol within the limits of the national guidelines: men and women are advised not to drink more than 14 units a week on a regular basis. If you regularly drink as much as 14 units a week, you should spread your drinking over 3 or more days.

Social Work

We appreciate that coming into hospital can be stressful for both patients and their families for a whole variety of reasons. The renal social worker can give advice and support on a range of personal, emotional and practical matters. You may already have met with them during your spell on dialysis. You can reach them at the Social Work Office opposite The Sanctuary at the RIE, or telephone

0131 242 7850. Information related to Welfare Benefits and a few general guidelines are listed below. 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 receive Income Support, Income Based Job Seeker's Allowance, Income-Related Employment Support Allowance (ESA) or Guarantee Pension Credit, you should 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.

You may also qualify for help if your income is £15,276 or less and you also get either Child Tax Credit (with or without Working Tax Credit) or Working Tax Credit with the disability element or severe disability element. If you are on a low income but don't get any of these benefits or allowances, you may still be able to claim travel costs through the NHS Low Income Scheme.

To apply for the NHS Low Income Scheme, you need to fill in form HC1. You can order form HC1 by phoning the NHS Patient Services Helpline on 0845 850 1166 or get it from the RIE Social Work Department. Your form will be assessed and if you're entitled, you'll get a certificate that confirms whether you receive full or partial help with your hospital travel costs.

Unfortunately, fares are not paid for those visiting you. If, however, they receive Income Support, they should contact 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, speak to 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 and ESA: if you receive Income Support and ESA, you should advise your local Benefits Office of your admission to hospital. Your benefit will continue for six weeks before being reduced.

PIP (Daily Living) and Attendance Allowance: These benefits will stop after four weeks in hospital. You should, once again, advise your local Benefits Office of your admission. Carer's Allowance will also be withdrawn at this four-week stage.