A Patient’s Guide to Kidney Transplantation

Introduction
Kidney transplantation is now a common operation, and the vast majority are successful. There are some risks and side-effects, but for many people the benefits outweigh the risks. Reading this will help you understand the main issues and considerations involved and there is a list of recommended reading and websites at the back for more detailed information; you may have to ask your renal nurse for other sources of information produced in your own country.

Currently most kidneys for transplantation come from people who have died in hospital, and their relatives have wanted their organs to be used to help others. They are called cadaveric donors. In many countries, there are not enough kidneys available, and we all have a duty to look after these precious resources.

Living Donors
An increasing number of kidneys come from living donors who have a close relationship to the recipient. The success of these transplants is slightly better than for cadaveric donors. Living donors undergo many tests to ensure that they understand the risks, are fully fit and with two well-functioning kidneys before they can donate.

Transplantation means freedom from dialysis and its fluid and diet restrictions. However, there are many tablets which must be taken every day, and care should be taken to eat healthily. Regular clinic visits are also essential.

Please note:
Some people find that their income is reduced as a result of transplantation; this may be due to government policy in your country, or some people will have to take time off work (6-12 weeks) because of the surgery and the clinic commitments and may be penalised for this. The cost of public transport can be substantial if you are coming to clinic several times each week for a prolonged period. Some people may be entitled to re-claim expenses on travel so should keep any receipts. Hospital transport is usually only provided in cases of medical need. In many countries, transplanted patients in employment will have to pay towards the costs of their medicines.

Prior to Kidney Transplantation
Once the medical referral for you to be considered for a kidney transplant is received, a clinic appointment will be arranged for a transplant assessment.
During this appointment the transplant procedure will be explained and the risks and benefits of kidney transplantation discussed. Your general medical fitness for the operation will be assessed and the doctor may recommend that further medical tests be carried out, for example an electrocardiogram (ECG).

If you are considered medically fit for the procedure the Transplant Clinic will request a blood test that will determine your blood group and tissue type. Once this result is available it will then be forwarded to the national organ allocation service and your name added to the list of those waiting for a kidney transplant. You should then receive confirmation that your name has been added to the list.

The kidney transplant waiting list works on the principle of finding the right patient for the right donor kidney. The ‘tissue type’ of the donor kidney is matched with that of the transplant patient and the patient with the closest match will be selected to receive the kidney. There are other considerations such as blood group, how long the kidney has been out of the body, time spent on the waiting list and others but the tissue type match is the main criteria. Some patients will have antibodies which result from blood transfusions, previous transplants or from pregnancy. These antibodies may limit the kidneys available. It is very difficult to predict when a suitable kidney will become available and some patients will find that they wait longer than others.

If you are not considered medically fit for a kidney transplant it is possible that you may feel disappointed and upset. If this is the case Transplant Clinic or your renal nurse should be able to offer further clinic appointments as needed to provide support during this difficult time. In addition, many centres have access to a counsellor, specialising in the needs of renal patients.

**Pre-transplant assessment**

**Blood Group**
Blood group is an inherited characteristic of red blood cells, and describes certain proteins, like labels, on the blood cell. It stays the same throughout life and there are four blood groups A, B, AB and O. Blood group A is “labelled” with A, group B with B, group AB has both and group O has neither. Group O, because it has no “label”, is compatible with all other groups. Conversely, group AB has both “labels” and so can only be given to someone who is already AB. In white Europeans O and A are most common and in the Asian population B and AB are most common.

**Tissue type**
Each person also has an inherited set of characteristics or “labels” (antigens) on the surface of most cells. This tissue type is made up of many characteristics, six of which are important in transplantation.

The tissue types that are important in transplantation are A, B and DR. Most people have two of each, one from each parent. There about 20 different versions of each type, hence there are millions of different possible tissue types. In the case of kidney transplants the match does not have to be perfect, however, overall, the greater number that are the same, the better the long-term result. Good results are still achieved with no match at all in living donor transplants, because the kidney is so healthy. The success rate for a living donor transplant with no match is about the same as that for a cadaveric kidney transplant with a 6 out of 6 match.
One issue about receiving a kidney with some tissue type mismatches is that you will make antibodies to those tissue types. Should you need another transplant at some point in the future, your options may be limited if you have antibodies to certain tissue types.

**Matching**
Kidneys are allocated to the person who is the best match in terms of blood group and tissue type.

Children are given priority for kidneys as they do not tend to thrive on dialysis and may suffer growth impairment.

**Transplant List**
Waiting for a kidney can take a long time, you should not put your life on hold while you wait. It will help you in the long-run, whether transplanted or on dialysis, to look after yourself now.

Regular exercise will keep you fit and help maintain healthy bones. Keeping to your diet so that calcium and phosphate are as normal as possible is also important in keeping bones healthy and strong.

Building up too much fluid on dialysis (becoming overloaded) over time will cause the heart to become enlarged and weakened. This will increase your risk of heart failure or death.

Smoking is very bad for your circulation and should be stopped as soon as possible.

Having a transplant and taking anti-rejection drugs can make poor circulation even worse.

Regular dental checks are advised to ensure teeth and gums are in good condition; bad teeth can be a source of infection and a common side-effect of one of the anti-rejection medicines is overgrowth of the gums.

Having the correct contact details on the renal unit computer is vital; keep us up to date with contact details and ensure we can always get hold of you, even in the middle of the night.

Be ready to pack a bag with nightclothes, dayclothes, medicines, toiletries, slippers, books, personal stereo etc.

Tell your employer that you may suddenly be called away. You are likely to remain off work for 6-12 weeks.

Planning for being called – organise someone to look after your family/pets/home.

When planning a holiday let your renal unit know your contact details. If you go abroad, you may be suspended until your return. Consider that you will have to cancel if a kidney comes up – you will have to check with your insurance company about whether this could be covered.

Sometimes a patient is suspended from the transplant list; this means that they are no longer being considered for a kidney, usually temporarily. Suspension from the list can happen if you are unwell or it is thought that a transplant would be too risky, or if you fail to look after yourself. You will need to be reviewed in clinic to see if your name can become active again on the list.

**Plan for being called up**
When you are telephoned you will be asked to make your way to the transplant ward. On arrival, various blood tests will be done, dialysis may be arranged and you will be checked to ensure you are fit for surgery. It takes about 6 hours to get the result of the crossmatch test. If this is positive you will not be able to have the kidney, as your body would reject it.
straight away, and you will simply return home to await your next chance. If all tests are good, the operation will be arranged as quickly as possible.

**Suspension from the list**
This can happen if you are unwell or it is thought that a transplant would be too risky. You will need to be reviewed in clinic to see if your name can become active again on the list. You may also decide yourself that your name is suspended, for any reason, but most commonly this is done for social reasons.

**Surgery**
The operation takes about three hours. If your own kidneys are very large or chronically infected then one or both may be removed either before you go on the list or in the future; however most people keep their own kidneys.
The transplant kidney is placed as shown in the diagram, it usually has one artery and one vein which are connected to an artery and vein in your pelvis, and a ureter (urine tube) which is connected to your bladder. A plastic tube called a stent is often used to support this bladder connection and will be removed about 6 weeks after the transplant. While you are asleep, a bladder catheter will be inserted so that the urine output can be measured and to avoid any build up of pressure on the new ureter. A neck line is also inserted, similar to those used by some haemodialysis patients, and a drainage tube will be left close to the kidney.

![Abdomen showing native and transplant kidneys](image)
On the ward
You will be monitored very closely to begin with. You will be able to sit out for a short time the day after surgery. Within four days the wound drain, catheter, central line and drip have usually been removed. Most people go home within one to two weeks, once they have learnt their medications.

Complications
A chest infection is reasonably common after a general anaesthetic; you should do deep breathing exercises and coughing while clutching a pillow for a few days after the operation.
A pocket of fluid (lymphocoele) around the kidney is common after surgery and this does not normally cause any problem. Sometimes, however, a large collection of fluid can cause discomfort and swelling of the leg, or even affect the flow of urine. In this case, a tube will be inserted and left in place to drain the fluid. This tube may be left in for weeks until the fluid dries up.
If the surgery is technically difficult, for example if the artery and vein are small, or fragile, then there is a higher risk of failure. The most common cause of failure is a blood clot forming in the kidney's blood supply within a day or two of the operation. There is tiny risk of transmission of disease from the donor. Donors are screened by blood tests, to ensure viruses such as HIV and Hepatitis are not present, and also by lifestyle – a donor considered to have had a high-risk lifestyle would not normally be used for kidney donation. Kidneys from donors who have had certain types of cancer are also not used. If there are any concerns about a kidney, you will be informed before you accept it.

Outcomes
After one year, about 85-90% of Cadaveric kidney transplants are functioning. The main causes of failure are blood clots and kidneys which never function properly. As much as possible is done to increase the chances of each kidney working, and if anything is known beforehand which makes the surgery more risky then you should be informed before the operation.
After ten years about half of the kidneys are still working. In general, the better a kidney is in the early stages the longer it lasts.

Rejection
Kidneys are rarely lost due to rejection. About 15% of patients experience rejection in the first few months. Mild rejection is treated with a drip of strong steroids over three days; severe rejection requires a ten day course of a stronger drug. Obviously, side-effects are worse if you have these extra treatments but they are very successful in stopping rejection. Newer treatments are also being developed.

Infection
The anti-rejection drugs act on your immune system to prevent your body attacking the kidney. It is a matter of getting the right balance, so that rejection is prevented but your immune system can still fight germs. The anti-rejection drugs will make you more at risk of infection but in practice only one disease is common, a viral, 'flu-like illness called CMV (cytomegalovirus). CMV disease is most common about 6 weeks after the transplant; if you are unwell with this you may have to come into hospital for a 12 day course of an anti-viral drip. The disease can be caused by reactivation of a virus you already have, or it may be transmitted with the kidney. People at high risk of this are given preventative tablets for three months or more.
In the long-term the most common problem with infection is an increased susceptibility to tummy upsets, and in women an increased susceptibility to urine infections. You should not ignore a high temperature (over 38 degrees C).

**Clinics**
For several weeks after the transplant you will have to come to clinic several times each week. At each clinic someone will look at your weight, blood pressure, blood tests, urine test and medicine list. Gradually, the intervals between visits increase. By the end of the year most people will attend about once monthly. Eventually most people attend every three months. Clinic attendance is vital as part of your care and is an investment in your future. Please remember to bring your ciclosporin, rapamune or tacrolimus to the clinic so that you can take it AFTER the blood test. If you have any questions or worries it is a good idea to write them down and bring them with you.

**Medicines**
You have to take a large number of tablets and be prepared to take them every day for the rest of your life. The biggest cause of transplant failure after the first few months is due to patients not taking their tablets! You need to take time to get to know all your tablets well. Learn them by name and dose, you will need to know them or have a list for each clinic visit. You should never run out of tablets. Although the medicines stop your body from rejecting the kidney, and also help you to remain healthy, all medicines have side-effects.

**Anti-rejection drugs**
*Neoral* (ciclosporin) causes increased hairiness, hot flushes and enlarged gums, and high blood pressure
*Tacrolimus* (*Prograf, FK506*) carries a risk of sugar diabetes in vulnerable patients
*Sirolimus* (*Rapamune, Rapamycin*) can cause acne, anaemia, low white blood cells
*Mycophenolate mofetil* (*MMF, Cellcept*) causes tummy upsets and can cause anaemia and low white blood cells
*Azathiaprine* (*Imuran*) can cause anaemia and low white blood cells
*Prednisilone* (*steroids*) carry a risk of diabetes, especially if you are obese or have a family history of diabetes. They also cause hunger, swelling of the face, emotional disturbance, acne, stomach irritation and osteoporosis. In the long-term they cause thinning and fragility of the skin, bruising, and worsening of cataracts.
*Methyl Prednisilone* is a stronger steroid treatment used in a drip to treat rejection.
*Basiliximab* (*Simulect*), *Dacluzimab* (*Zenepax*) are anti-rejection treatments used while you are in hospital and are relatively free of side-effects.
*ATG* (*Anti-Thymocyte Globulin*) is used in hospital to treat, or to prevent, severe rejection. People usually feel unwell for the first few days with ‘flu-like symptoms. This drug strongly reduces the immune system.

All of these drugs reduce the body’s ability to defend itself from infection. This increases the risk of viral illnesses, bacterial or fungal infections and, after a long period of time, increased risk of certain types of cancer. Cancer of the skin, related to a skin virus and exposure to sunlight, is the only common cancer and it is generally easy to treat. Patients from sub-Saharan Africa and the Mediterranean are at increased risk of a type of skin cancer called Kaposi’s Sarcoma. This is caused by a virus which is common in those...
geographical areas. It can be difficult to treat, and if reduction of immunosuppression, chemo- or radiotherapy cannot control it then it may be necessary to lose the transplant and return to dialysis. Cessation of immunosuppression will allow the body to clear the disease.

If you miss a dose of an anti-rejection medicine, you should take just the normal dose on schedule. If you are being sick, you should not take extra tablets unless you actually see that you have vomited up the tablet. If you are not able to keep your tablets down, you must contact your clinic, you may need to come in for treatment.

Additional drugs which may be used

**Aspirin** – to reduce heart and circulation problems in the long-run. Kidney patients on the whole are at increased risk of these. It can irritate the stomach lining and cause increased bruising.

**Statins** – to lower cholesterol and reduce the risk of heart and circulation problems by reducing inflammation in the circulation. Can cause muscle damage

**Calcichew D3 Forte** – a calcium/vitaminD tablet to help maintain healthy bones

**Pamidronate** – a drip, which may be given after the transplant, to move calcium into bones and make them stronger. It can cause a temporary low calcium, and can cause mild aches and pains for a few days.

**Co-trimoxazole** – an antibiotic many centres prescribe for the first few months to prevent certain infections

**Ranitidine** – reduces acidity in the stomach to prevent irritation by steroids and aspirin.

**ACE-Inhibitor** – a type of blood pressure tablet which, in addition to lowering blood pressure, has a protective effect on the kidney. Some people cannot tolerate this because of dry cough, a deterioration in kidney function or low blood pressure.

**Skin care**

Skin care is very important after the transplant because of the side effects of the anti-rejection medicines. The drugs required to prevent your immune system from rejecting the kidney will also prevent the immune system from eliminating warts and skin cancers. Most transplant patients develop skin warts after a year or two. Usually these are no more than a minor inconvenience; however some patients may develop large numbers of very troublesome warts over large areas of the body. These warts tend to be very persistent and difficult to treat. Skin cancer is far more common in transplant patients than in the rest of the population. The cancers usually begin to appear between five and 10 years after the transplant, but they may occur much sooner. Skin cancers can be treated quite easily if they are detected early. If they are neglected, or if they become numerous, treatment may be extremely difficult, involving extensive surgery and skin grafts. Occasionally these cancers can be fatal.

If you have had a lot of exposure to the sun you may be at an increased risk of developing skin cancer. High exposure is considered to have occurred if, for example, you have worked outdoors for five years or more, or have spent a lot of time sunbathing, gardening, or outdoor sports such as golf or sailing. If you have a fair skin, freckles, red or fair hair, blue eyes, burn easily, or tan without difficulty you are particularly at risk.

Skin cancer is unusual in people with low sun-exposure, that is, those who have indoor jobs and who do not sunbathe or take part in activities in the sun for more than an hour or two each week, and who have their holidays in cool countries. Those people with low sun-exposure do not get many warts.
You should keep out of the sun between 11.00 am and 3.00 pm, April to October. If you have to be out during these times:
Keep in the shade as much as possible
Wear a wide-brimmed hat
Wear a long sleeved shirt or dress
Wear trousers or a long skirt or dress, not shorts
Wear a strong sunblock (factor 25 or more) which protects against UVB and UVA. You may be able to obtain sunblock on prescription from your doctor.
You need to apply sunblock to all exposed skin, especially the back of the hands, the face, neck and ears.
Sunscreen should be reapplied every three hours even if you do not feel that the sun is hot. It is difficult to identify skin cancers at an early stage. Some may look like a scaly lump, very much like a wart. Others look like moles which may have enlarged or become more deeply pigmented. Because of this difficulty in identification we recommend that you see a Dermatologist (skin doctor) about three months after your transplant. On the basis of your age, skin type, and your degree of sun damage the dermatologist will then decide how often you need to be seen in the future to ensure that any cancers are detected early.

If, at any time, you are worried that you may have skin cancer, ask the doctor or nurse in clinic to refer you to a Dermatologist.

Cancer
The risk of some other types of cancer, apart from skin cancer, is increased after transplantation, because you are immunosuppressed. Most of these are only slightly more common than in the general population. Less than 2% of patients develop a type of cancer of the white blood cells, usually related to the Glandular Fever virus. When this occurs within a year or so, it is usually easy to treat by reducing the immunosuppression. If it occurs later then it is more serious and may require radiotherapy or chemotherapy and can be life-threatening.
Women are at increased risk of cervical cancer and should have annual smear tests. A healthy lifestyle will reduce the risk of cancer.

Travel
You may find it difficult to drive for a few weeks afterwards because of discomfort in the wound. Some car insurance policies have special conditions about not driving after a general anaesthetic so you should check your policy.

You should not plan any long trips for a year after your transplant. Visits to developing countries are particularly risky because of the incidence of diarrhoea and vomiting, which causes dehydration, and the difficulty of finding expert help. On a flight, air pressure (and oxygen level) is low and moisture will be sucked out of you – it is important to drink extra water. Leg exercises are also important for your venous circulation; drinking plenty of water and taking aspirin will help prevent deep vein thrombosis (blood clots). Health insurance is strongly advised.
You will also need advice on any vaccinations which may be required for some countries. You must not have live vaccines (because you are immunosuppressed).
Returning to work
You should be able to return as soon as you feel able, normally 6-12 weeks. Remember you will have to attend frequent clinics for the first months.

Sex
You may be surprised at how quickly your sex drive returns, as does your fertility. Both men and women should wait for a year before trying to have children, in this time your immunosuppression will have been reduced, the kidney will have settled down and your medication can be reviewed. Birth control can be discussed in clinic.

Diet
Most transplant patients put on some weight; some more than others. This is due to the increased appetite following the correction of kidney failure, the side-effects of steroids and the fact that the diet is no longer restricted. You may be restricted for a short time following the transplant, but a dietitian should be available for advice. The important message to remember is that a healthy, well-balanced diet will keep your weight stable. Those who gain too much weight are eating too much.
Your diet should include more vegetables, fruit, pulses (beans, lentils) and salads.
Wholemeal bread and rice should be eaten regularly.
You should:
Not eat between meals (no snacks)
Cut down or avoid sweets, biscuits, cakes and sugary drinks
Avoid fatty and fried foods; use butter and margarine sparingly
Eat 5 portions of fruit or vegetables daily
Exercise daily
Drink alcohol in moderation. Alcohol has a high number of calories.

Drinking
Transplant recipients should normally drink about 2 litres daily. More is needed if the weather is very hot, if you have a high temperature, if you are flying or at high altitude, if you have diarrhoea or vomiting, and if you are drinking alcohol.

Fitness and exercise
Exercise helps you feel better in body and mind.
It helps you to relax
It strengthens muscles, joints and bones
It helps your heart and circulation work more efficiently, and helps protect against heart disease
It need not cost anything
It gets easier the more you do it
You can start exercising anytime you are ready. As your life returns to virtually normal, exercise can be fitted into your daily routine and increased gradually as you feel able.

Fitness is three things: suppleness, strength, stamina

Whether you are young or old, everyone can do some exercise – it is never too late.

Getting started can be a problem, but it does not have to be difficult. All you have to do is simply walk more. When walking, walk faster until you can walk briskly. Another idea is to use the stairs instead of lifts, and walk up escalators. The Golden Rules are:
1. get moving
2. build up gradually
3. exercise regularly
4. keep it up

Suitable activities include walking, swimming, cycling, golf, jogging, bowling, badminton, tennis, yoga, squash, aerobics, exercising at home to videos.
Unsuitable activities are contact sports such as martial arts, rugby

**Smoking**
Giving up smoking increases the chances of living a longer life, and it is probably the greatest single thing you can do to improve your health.
Smoking can cause lung cancer, high blood pressure and circulation damage. This damage to your blood vessels can cause angina and heart attacks, pain in the legs on walking even short distances, and impotence. Kidney patients are already in a high risk group for heart and circulation problems.
When you stop smoking there are many benefits, the body begins to repair itself and return to normal. You will benefit from:
Reduction in smoking related diseases (lung cancer, heart and circulation problems)
Hair, skin, clothes and breath no longer smell of stale tobacco
Facial skin loses it's dry, wrinkly, smoked appearance
Breathing improves and you can cope with sudden exertion
Reduction in phlegm and loss of smoker's cough
Reduction in anxiety over health and wellbeing

You can only feel good for having stopped smoking.

**Dental care**
You should continue to visit your dentist regularly, at least every six months. It is particularly important to look after your gums if you are on ciclosporin, which can cause them to grow over the base of your teeth. You should brush your teeth mornings and evenings and floss daily.
The dentist will give you antibiotics, usually a single large dose, before performing any procedure where bleeding will occur. This is to prevent problems from bacteria from getting into your bloodstream.

**Personal care**
You can still bathe/shower daily but may need a more gentle soap. It is advisable not to have your hair permed or treated for three months as the high doses of immunosuppression may make your hair brittle and your scalp more sensitive to the agents that are used.

**Concerns, Questions and Queries**
If you have any health concerns regarding your kidney transplant the Transplant Clinic is able to offer telephone advice and arrange additional appointments as needed.

If you have a temperature and/or are feeling unwell please contact the Transplant Clinic as soon as possible and be prepared to come to the hospital if requested. In the first few
months you should pay particular attention to any high temperature, breathlessness, pains in the kidney or if urine output halts.

**Contact Details**

Please remember - If you have had a kidney transplant, or you are on the waiting list for a kidney transplant it is important that the Transplant Clinic has up to date home, work and mobile telephone numbers.

**Information for men post transplant**

Sex life is usually better after a transplant than when on dialysis, although it is not guaranteed. The period you have spent with kidney failure, any other health issues, and some of the side-effects of the tablets can all have an effect on your sex-life. Contraception should be used even if you want to have a baby; we recommend waiting for one year before trying for a baby. You should also tell the clinic before you try in case some of your tablets need adjusting. For men who have trouble with their sex-life, you should ask if there is a specialist clinic you can be referred to.

**Information on pregnancy for women of child-bearing age**

Following the transplant your hormones gradually return to normal, so you could become pregnant. It is important to use birth control so that you do not compromise your own health, the transplant and risk abnormalities in a baby. Most centres recommend that you wait at least one year before trying to become pregnant, so that immunosuppression levels are optimum, that your kidney function is stable and that your body is back to normal. If you become pregnant before this you may be advised to abort. You should not plan to become pregnant without discussing this with your doctors and nurses. Some of your medications may need to be changed as they can cause foetal abnormalities.

A pregnancy should only be considered if you have “good stable kidney function”. The doctors will discuss this with you.

There is an increased risk of the baby being born early (prematurely); about half of all babies born to renal transplant mothers are delivered before 37 weeks, and half are of low birth weight for their dates. Babies quickly put on weight and although may be born small they develop normally.

There is no increased risk of malformation, deformity, Down’s syndrome or spina bifida. The obstetric team will advise you of any tests or investigations you should undertake; these will be due to your age or familial risk rather than because you have a transplant.

There is no increased risk to you because you except that you may be compromising the transplant itself.

There is a slight risk of rejection while you are pregnant and this is why you will be followed by the transplant clinic at the same frequency as the obstetric team, so that your renal function, blood pressure and medication can be monitored. During pregnancy your renal function may improve, this is transient and should return to your normal pre pregnancy levels very soon after delivery.

The majority of patients will have a Caesarean section but if you feel strongly regarding a normal delivery you will need to discuss this with the obstetrician (remember about 50% of babies are born prematurely). Sometimes the position of the transplanted kidney prevents the baby’s head from ‘engaging’ (dropping down into the pelvis ready for delivery) so a Caesarean section is the only option. Most mothers opt for a planned Caesarean section; if
the delivery is planned it is considered to be the safest option for you, the baby and the kidney as you can have experienced personnel to carry out the operation and the transplant team are immediately available.

It is not possible breast feed your baby. The anti-rejection drugs you are taking are present in breast milk, therefore your baby would be immunosuppressed.

Studies
Transplant services strive to find the safest, most effective drug regimes following renal transplant. As part of this studies are often carried out on new or different combinations of medicines – all of these have already been shown to be safe and effective in comparison to our current medicine regimes. You may be asked if you are interested in participating in a study, but will not be under any obligation to do so.

Guidance on writing to your donor’s family
Once you have received a new transplant kidney, everyone hopes for a good recovery, even if the transplant was not successful. For those who received a cadaveric kidney, permission to donate that kidney was given by those closest to the person who died, and they will be told brief, anonymous details about how the kidney was used.

In the past, when previous patients have received a transplant, even if it was not successful, they often ask about their donor and many want to say “thank you” to the family of the donor. This section explains how these letters are processed and what may happen after your letter is passed on to the donor’s family.

Research has shown that donor families react most positively on receiving such letters.

The mother of a 25 year old donor said, “You just need to know how the recipients are doing. I made copies of my letter and sent them to family and friends. The letter opened a lot of eyes. More people are going to donate because of it.”

The husband of another donor said, “It feels good to know that the recipients of the gift of life appreciate what has been done for them.”

Another family said, “I guess I never really expected to hear from anyone and when I received the letter I suddenly realised what the donation meant – it really happened – I was joyful.”

What is the donor family told about me?
Within a short time after donation, donor families receive a letter from their local transplant co-ordinator, thanking them for their donation. In this letter they are given outline information about the patient who has received the transplant. In general, this includes your age and gender, whether you are married or single and if you have any children. They may be told how long you have spent on the waiting list. They are not told your name, where you live, or any other details which may identify you.

Can I find out about my donor?
Not every recipient asks about their donor, but if you want to know, please do contact your transplant nurses. You will be told your donor’s age, gender and some general information
about the cause of their death. You will not be given their full name or told where your donor lived.

**When can I write to the donor’s family?**

It is probably best to wait until after your discharge from hospital before writing to the family. Most people write between two and six months after their transplant operation. However, you can write at any time, months or even a year after your transplant. Most families will appreciate the gesture at any time but the transplant co-ordinator will always check with them first before forwarding any letter.

**What can I say in the letter?**

The letter should not identify you apart from your first name – no addresses or telephone numbers and no mention of your renal unit should be given. This is to protect confidentiality. Please do not seal the envelope, as the transplant co-ordinator that deals with the donor family will want to check the letter before passing it on. We would also prefer that you don’t date the letter as we may be unable to pass it on for some time and would not want to cause any distress by its delay.

The letters normally start with ‘Dear friends’ or ‘Dear family’, and an introduction, for example, “My name is Tom, I am 36 years old and have been on dialysis for four years. I am married with three children and have not worked for a few years due to ill health.”

Most people then describe what life was like when they were on dialysis and explain the positive changes that have occurred since the transplant operation. Everyone says “thank you” in a different way, and everyone says that they find this letter difficult to write, but it will be very much appreciated.

These letters should be given to the transplant nurses who will send it to the transplant co-ordinator who has been looking after the family.

**What happens next?**

Occasionally you will hear no more after this. Occasionally the co-ordinator will hear directly from the family, who may ask that their thanks be passed on verbally to you for your letter. Very occasionally, the donor family will reply, to thank you and to ask you to write again in the future to let them know how you are. All letters will continue to be passed via the transplant co-ordinators unless a time comes when both you and your donor’s family decide to write directly to each other – this happens very rarely and must first be discussed with your transplant team.

**For more advice and information**

If you need any further advice or information, please contact your transplant team.

**Useful websites: United Kingdom**

National Kidney Federation (nkf) tel.01909 481723/6010209, website: [www.kidney.org.uk](http://www.kidney.org.uk), email: nkf@kidney.org.uk

For leaflets, information and advice. They also campaign for improvements in renal services.

UK Transplant (UKT)
www.uktransplant.org.uk
The NHS organisation responsible for organ donation and allocation of organs across Britain.

Transplant Support Network (TSN)
www.transplantsupportnetwork.org.uk
A national network of volunteer transplant patients and their carers who can offer the benefit of their own experience.

BODY (British Organ Donor Society)
www.argonet.co.uk/body
this is aimed mainly at organ donors and recipients, their relatives and friends.

TIME (Transplants in Mind)
www.timeuk.org
A conglomerate of charities specifically for patients on waiting lists for transplantation. Their main goal is to raise public awareness about transplantation.