LIVING KIDNEY DONATION

The Exceptional Gift

Living Kidney Donation and Transplantation Information for Healthcare Professionals in Scotland

www.livingdonationscotland.org
Email: livingdonationscotland@nhs.net
Call: 0131 242 1703 or 0141 451 6200

Healthier Scotland
Scottish Government

Introduction

The Living Donation Scotland Project Board aims to improve access to living donor kidney transplantation throughout Scotland. This resource has been developed to provide an overview of the process and update healthcare professionals on the many changes there have been in recent years.

Jen Lumsdaine
Living Donor Transplant Co-ordinator
Living Donation Scotland Project

We encourage all potential donors to be referred to the renal and transplant teams – every potential donor is considered within guidelines that are continually re-evaluated. Early referral of recipients increases opportunity of pre-emptive living donor transplantation.

This written resource is available on the Living Donation Scotland website at www.livingdonationscotland.org. Contact details will be kept updated for your information.

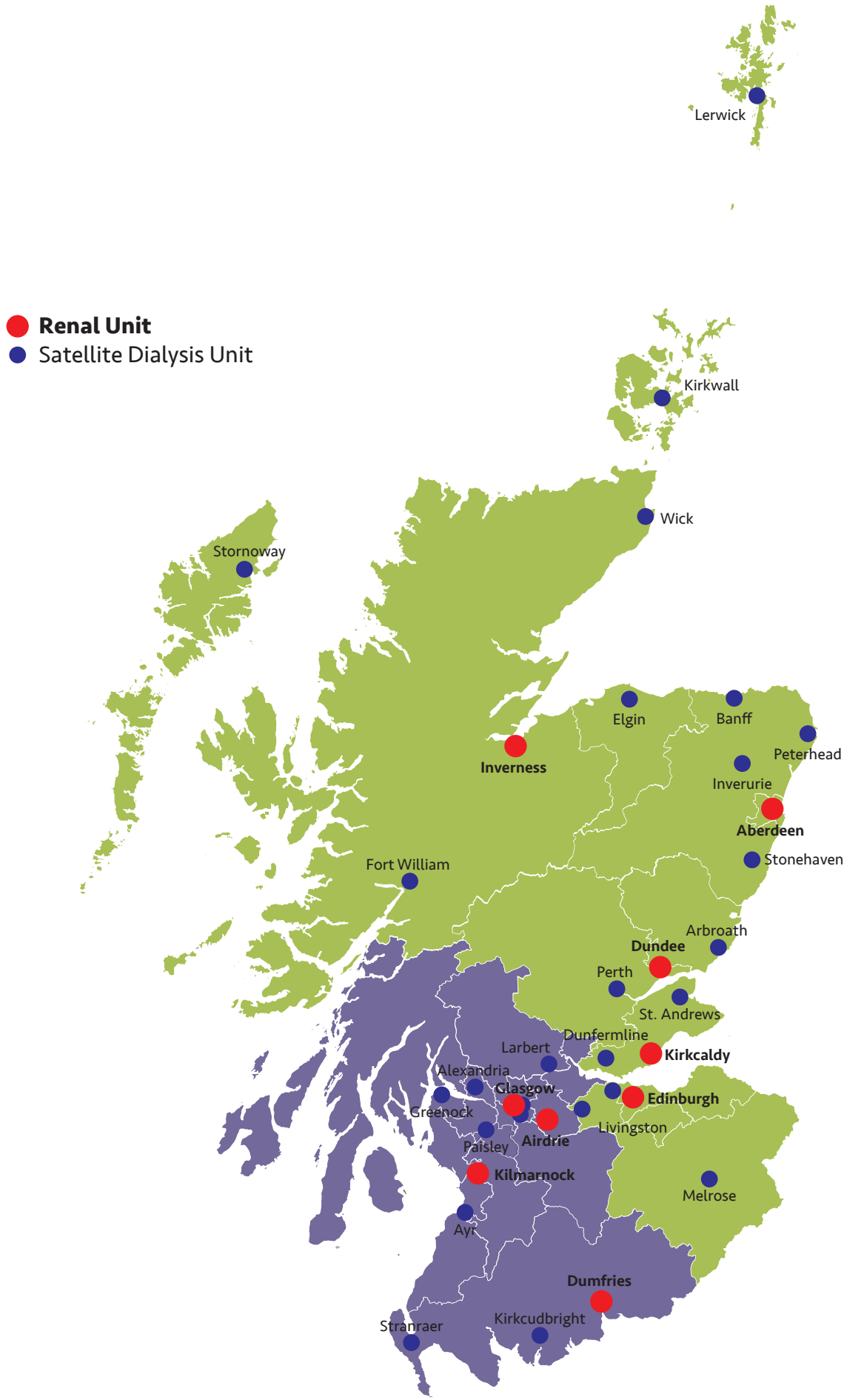
Living Kidney Donation Contacts

Hospital	Tel No
Aberdeen Royal Infirmary	01224 559 497
University Hospital Crosshouse	01563 825080
Dumfries and Galloway Royal Infirmary	01387241079
Fife Hospitals	01592643355 Ext 20176
University Hospital Monklands	01236 712 648
Ninewells Hospital Dundee	01382 633 897
Raigmore Hospital Inverness	01463 706689

Transplant Units

Edinburgh Transplant Centre	0131 242 1703
Queen Elizabeth University Hospital Glasgow	0141 451 6200

Renal Units in Scotland



Map source:
Scottish Renal Registry

What I say to a Potential Donor

Potential donors will initially contact the Living Donor Transplant Co-ordinators who then initiate a series of preliminary assessments to ensure that there are no absolute barriers to considering donation.

When a potential donor attends the clinic for the first time, I do not tell them anything good about living donation! This is because I need to ensure that any potential donor fully understands the implication of donation, both in terms of immediate and long-term risks. I also make it very clear that for any potential recipient, living donation is without a doubt the best treatment option for renal failure.

I explain the risks associated with the donation procedure and advise that this is an operation for someone who is otherwise healthy and that there are no medical benefits for them.

Very few people develop major complications. However sometimes they could be quite serious and may have lasting effect on the quality of life long-term. Major complications can happen in less than 3:100 cases whilst some smaller complication may be encountered in every 5-8:100 donors. I also advise that long term there is a small risk of kidney failure (0.1 to 1:100) and this may be due to surgery or post-donation lifestyle choices.

I tell the potential donor that nowadays the operation is carried out by laparoscopic (keyhole) surgery and explain the various approaches to this surgery which is practiced around the UK and specifically in our Unit.

Finally, I make potential donors aware that during the investigations things may become apparent which may not allow us to proceed with donation safely.

Key Information

- The kidney is removed by laparoscopic surgery.
- Donors do not proceed with donation unless all test results are satisfactory and the multi-disciplinary team, donor and recipient agree to go ahead.
- The routine tests to assess a donor usually take **3-6 months**.
- Usually the donor is advised to arrange **2-3 months** off work following donation, depending on their occupation.
- There is a scheme in Scotland for reimbursement for loss of earnings.
- All potential donors should be referred to the renal and transplant teams.

Mr Gabriel Oniscu
Consultant Transplant Surgeon
Royal Infirmary of Edinburgh

What I say to a Potential Transplant Recipient

A living donor kidney transplant is the best form of kidney replacement therapy in those who are deemed fit enough for transplantation.

This is because patients who receive a living donor transplant tend to live longer and feel better than patients who have other forms of kidney replacement treatment, such as haemodialysis or peritoneal dialysis. It is better to get a transplant before needing to start dialysis, if possible. A living donor transplant has a much better chance of taking place before dialysis is needed than a deceased donor transplant.

Advanced chronic kidney disease affects the individual as well as their family and potential recipients are usually worried about both. I try to encourage my discussions to include at least one other person who is close to the recipient.

Before discussing living donor transplantation with a potential recipient, I try to find out about their particular circumstances. Each situation is different and I try to tailor the discussion accordingly. I encourage the recipient to talk to family and friends about the fact they are going to need a transplant. It is often difficult to start the conversation about needing a kidney transplant with those close to you who might be able to donate.

I reassure the recipient that we will look very carefully at the potential donor to ensure they are in good health and well informed. The risks to the donor are small and the donor potentially also has a lot to gain emotionally from donation by seeing the health of their loved one improve after successful transplant.

I emphasise that if a donor comes forward, they are not committing to anything and the transplant team will not put any pressure on them.

Key Information

- Recipients require support to raise the subject of living donation with their family and social networks.
- Donors do not need to be family members.
- If active on the transplant list, having a living donor in assessment does not impact on chances of receiving a deceased donor kidney.
- Patients can be listed on the deceased donor transplant list 6 months before requiring renal replacement therapy.

Dr Colin Geddes
Consultant Nephrologist
Queen Elizabeth University Hospital, Glasgow

Blood Group Compatibility

For a directed living donor transplant, which is a donor who is close to the recipient, such as a family member, partner or good friend, the first step in the process is checking blood group compatibility. For example, a blood group B recipient can receive from blood group O or blood group B.

If the donor and recipient are not blood group compatible then potential living donor pairs in this position need additional consideration. Options include the pair entering into the UK Living Kidney Sharing Scheme (UKLKSS) (see page 8) to find a compatible pair.

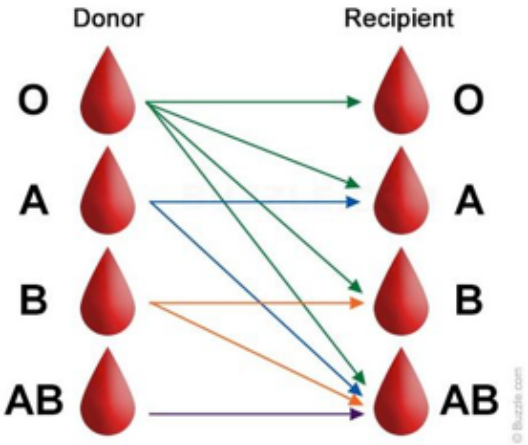
A direct donation (ABO incompatible transplant) between the pair, depending on how high anti-A/anti-B antibody levels are in the recipient may be considered. In carefully selected pairs, excellent outcomes can be expected with ABO incompatible transplantation, usually following pre-transplant treatment to deplete antibody levels in the recipient.

Therefore, blood group incompatibility within in a pair does not preclude transplantation.

Blood group by percentage of the population

Blood Group	Percentage of population in Scotland
O	50.4%
A	35.1%
B	11.2%
AB	3.3%

Blood Group Compatibility



Key Information

- Blood group incompatibility between a pair does not preclude transplantation.
- If the blood group is incompatible, the Kidney Sharing Scheme is considered as first option to find a blood group compatible donor.
- If no match is found, a blood group incompatible transplant can be considered if not deemed too high risk.

Dr Paul Phelan
Consultant Nephrologist and Renal Transplant Physician, Royal Infirmary of Edinburgh

Tissue Compatibility

In addition to ABO blood group compatibility testing, it is also important to consider human leukocyte antigen (HLA) compatibility between patients and their prospective donors.

HLA antigens are inherited by each parent and are similar to blood groups, but the HLA system has a much greater degree of variability. This variability means that different people, even when closely related, are likely to have different HLA types.

For living donation, having a different HLA type to a recipient is not in itself a problem. This means potential donors can be identified from not only close family members, but also from extended family and genetically unrelated individuals such as spouses and friends.

However, an issue that can occur is that the patient and donor may not be HLA compatible; which means the patient may have anti-HLA antibodies against the donor's mismatched HLA. Antibodies are formed when a patient is exposed to another antigen – this can be through blood transfusion, transplant or pregnancy.

Patients who have HLA antibodies against a donor cannot usually receive an organ from that donor. Testing of patients and potential donors within a specialised Histocompatibility and Immunogenetics (H&I) laboratory will identify whether a donor is HLA compatible with a patient or whether an alternative approach for transplantation, such as inclusion in the UK Living Kidney Sharing Scheme (see page 8), or a higher risk HLA incompatible transplantation, is possible.

Key Information

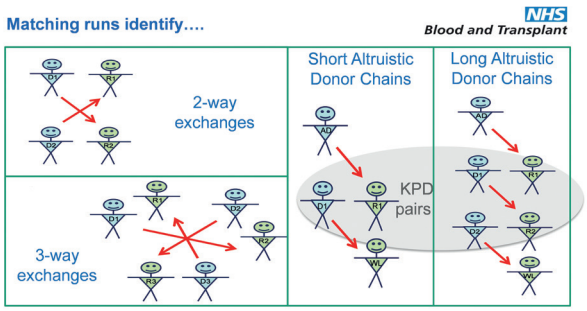
- Antibodies can develop if a previous transplant has failed due to blood transfusion because of pregnancy.
- The level of antibodies present can change over time and are monitored by the H&I laboratory.

Dr David Turner
Consultant in Histocompatibility & Immunogenetics
Scottish National Blood Transfusion Service

Kidney Sharing Scheme

The UK Living Kidney Sharing Scheme (UKLKSS) is a UK-wide kidney exchange programme in which donor and recipient pairs who are incompatible by blood group or human leucocyte antigen (HLA) type can participate to achieve a compatible or better matched transplant with a greater chance of a successful outcome.

Recipients may be registered with more than one donor to increase their options. Compatible pairs can also enter the scheme, usually to achieve a better age or HLA match, but any compatible pair can be included to facilitate a transplant for themselves and others.



In addition, non-directed altruistic kidney donors – people who choose to donate anonymously to someone whom they have never met before – are included in the scheme unless there is a high priority recipient on the national transplant list to whom their kidney would be offered first.

The scheme is administered by NHS Blood and Transplant (NHSBT). Every quarter, optimal combinations of transplants are identified from the pool of registered donors and recipients.

All transplant centres across the UK participate in the UKLKSS and designated weeks of surgery are pre-scheduled across the UK so that as many transplants as possible proceed within eight weeks of being identified. Simultaneous donor surgery within each exchange is preferred but may be staggered for logistical reasons with agreement from all donors, recipients and centres involved. Donor and recipient pairs usually remain in their own transplant centre and the kidneys travel. Recipient and transplant outcomes from the UKLKSS are comparable with those from direct living donor transplants where donor and recipient operations are performed in the same centre.

Key Information

- Incompatible and compatible pairs can enter the Kidney Sharing Scheme.
- A non-directed altruistic donor can trigger the chain for up to **3 transplants**.
- Matching runs take place **4 times a year**.
- Surgery will be scheduled within **8 weeks** of a matching run.

Lisa Burnapp
Lead Nurse for Living Donation
NHS Blood and Transplant

Living Donor Surgery

Living kidney donation is an operation that follows a detailed work-up to ensure that any donors have a very low risk of complications. This low risk applies both to perioperative complications and the long-term effect of living with only one kidney.

The living donor nephrectomy procedure is now almost exclusively carried out by a hand-assisted or fully laparoscopic (keyhole) surgery.

Patients are admitted the day prior to or the morning of the operation. Surgery is carried out under general anaesthesia and typically lasts around 2-3 hours.

Surgery is usually very well tolerated with patients returned to the high dependency unit or main ward on the afternoon of surgery. Pain and sickness are typical in the first 24 hours and are addressed with a combination of regional blocks, wound catheters and patient-controlled analgesia systems.

An in-dwelling urinary catheter is usually in place until post-surgery. Diet is usually re-established and mobilisation instituted shortly after surgery. Atelectasis and abdominal distension may delay progress, but most donors are discharged 3-4 days post-surgery.

After discharge, patients have open access to the unit with a contact number to arrange rapid reassessment if required. Significant complications are uncommon and most patients attend for follow-up at 6-8 weeks post-surgery. Almost all are fully recovered by 8 weeks and will be seen on an annual basis.

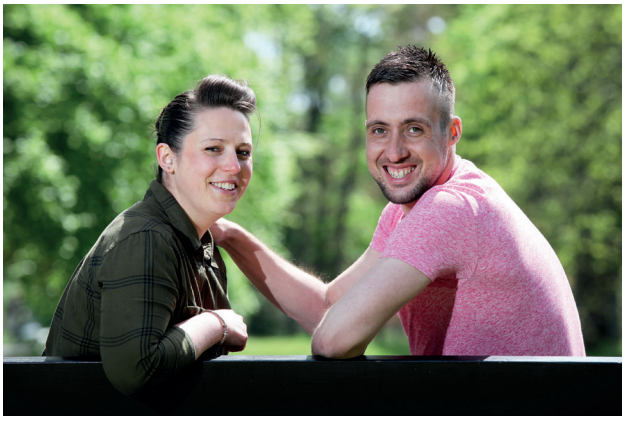
Key Information

- Surgery typically lasts for **2-3 hours**.
- Most donors are discharged **3-4 days** post-surgery.
- Most patients attend for follow up at **6-8 weeks** post-surgery.
- Almost all are fully recovered by **8 weeks** and will be seen on an annual basis.

Mr Marc Clancy
Consultant Surgeon and Clinical Lead for Transplantation, Queen Elizabeth University Hospital, Glasgow

PAUL'S STORY

Paul Duncan has been given a future after kidney failure put his life on hold, thanks to his friend Rebecca.



Rebecca Morrice and Paul Duncan

Rebecca donated a kidney to Paul in December 2017, describing it as the 'easiest decision she's ever made' and since the transplant operation, the pair haven't looked back.

Paul was diagnosed with IgA nephropathy in 2006 aged 18, and had to start dialysis in June 2016 when his kidney function rapidly declined – a period that he described as the worst of his life.

Struggling on dialysis and unsure whether a transplant would be possible, Paul had to give up work and ensure he kept himself as fit as possible to increase the chances of surgery success if it went ahead.

When doctors agreed Paul could be listed for transplant, six people came forward to get tested as potential donors, one of which was Rebecca, a former girlfriend who he met through work in 2010.

Thanks to the actions of Rebecca and the work of Paul's medical team, the transplant was successful, with Paul being discharged in January 2018, ready to start his new life.

Paul said:

"Rebecca saved my life and I can't put into words what it is she's done for me. Nothing I could ever do in the rest of my lifetime could repay her enough. She was so laid back through the whole process, nothing phased her at all which helped me through it".

Donor Follow-up

Following donation, all donors are expected to have life-long follow-up as per the UK Guidelines for Living Kidney Donation.

Initially, follow-up will be carried out by the transplant centre and then by the donor's local centre or GP.

The donor can expect to have their blood pressure, weight, biochemistry and full blood count, urine PCR (protein creatinine ratio) and urinalysis carried out at least annually for life.

It is important to note that a donor's creatinine will be higher (and their estimated Glomerular Filtration Rate (eGFR) lower) than pre-donation, and this can continue over time. This does not mean the donor has chronic kidney disease.

If the donor should develop a significant drop in their eGFR, significant proteinuria, hypertension or any other renal impairment, they should be referred to their local renal unit for further follow-up.

It is also important to note that should the donor develop any significant illness, including malignancy, the transplanting centre must be informed as this may impact on the health of the recipient and their kidney.

Key Information

- Donors should be seen at least **annually** for routine check.
- Living kidney donors who develop hypertension should have a low threshold for starting medication, aiming for good blood pressure control.
- NHS Blood and Transplant gather donor follow up data at **1, 2, 5, 10 and 20 years** post-donation, which is usually supplied by the Living Donor Transplant Co-ordinators.

Julie Glen
Living Donor Transplant Co-ordinator,
Queen Elizabeth University Hospital, Glasgow

Recipient Operation

Once the recipient has undergone full assessment and is fit for a transplant, and all the risks and benefits of a transplant have been explained, the date is identified for the operation to proceed.

Usually the recipient is admitted the day before the operation, for final check-up and to meet members of the team, such as the anaesthetist.

At the start of the operation, the surgeon will spend some time preparing the blood vessels for the operation. Some blood is 'borrowed' from the blood vessels supplying the leg, and the vessels are joined from the kidney on to those vessels.

Once the blood vessels are joined together by suturing, the blood supply is returned and the kidney will turn pink and perfused. Often the kidney passes urine on the operating table.

Once the surgeon is content with the kidney, the ureter is joined on to the bladder, so that urine can pass in the normal way. In most cases, a small plastic tube or stent is placed into the ureter, to protect the join onto the bladder.

After the operation, the recipient will be in recovery for a short while before being looked after on a high dependency unit or transplant ward.

Key Information

- The operation can take around **3 hours**, but that can vary.
- Anti-rejection drugs are started **immediately**.
- A urinary catheter will be in place for **5 days** after the operation.

Professor Lorna Marson
Consultant Transplant Surgeon
Royal Infirmary of Edinburgh

Recipient Follow-up

Everyone that receives a kidney transplant, whether from a living or deceased donor, is offered life-long follow-up by their local Transplant or Renal Unit.

Before the recipient is discharged from hospital, they are given verbal and written information on their new medications, including their immunosuppression, how to look after their health and transplant and contact details for their Transplant and Renal Unit so they can contact them directly if they have any concerns.

The recipient is advised on the importance of maintaining a healthy lifestyle, including specific advice on not smoking; protection from sun exposure; contraception and sexual health.

Transplant recipients must take their medicines exactly as prescribed. Some drugs used to prevent rejection must be prescribed by brand and not generic name as they are not interchangeable. Recipients are encouraged to learn about all of their medicines including doses and why they are taking them. Recipients will attend their renal unit several times a week initially after discharge. Transplants are very carefully monitored for signs of rejection. Early treatment of rejection is necessary for the long term survival of the kidney.

Key Information

- Recipients will have the stent removed within the first **6 weeks**.
- Recipients can usually return to driving about **6 weeks** following their operation.
- Recipients may require up to **3 months off work**, dependant on the individual and their occupation.

Dr David Walbaum
Consultant Nephrologist
Aberdeen Royal Infirmary

Non-directed Altruistic Donation

Non-directed altruistic donation involves living donors who are not known by the recipient. This type of donation is also referred to as anonymous, altruistic or non-directed living kidney donation.

The process of giving a kidney to a stranger has been permissible since 2006. Any individual who is considered a suitable living donor candidate can proceed to non-directed altruistic donation (NDAD). All NDADs are entered into the UK Living Kidney Sharing Scheme to initiate a chain of up to three transplants unless there is a recipient with higher priority for transplant on the national transplant list.

Non-directed donors must complete a comprehensive donor assessment, which includes the routine tests similar to those a directed donor undergoes. All altruistic donors have a mental health assessment. All donors require Human Tissue Authority approval (HTA) prior to a chain being identified. More information about the role of the Human Tissue Authority can be found on page 23.

Once a chain has been identified, a blood sample is taken from the donor and sent to the recipient's hospital to be tested with the recipient's blood to check the compatibility. Non-directed donors have their surgery in their local transplant centre and their kidney travels by road or air to their recipient.

The donor may never hear from their recipient. The gift of an altruistic kidney has a ripple effect of goodwill that extends beyond the recipient and their family. There can be an enormous sense of pride and satisfaction that donors feel after knowing they have given an exceptional gift.

Key Information

- An altruistic donor can initiate a chain of up to **3 transplants**.
- Altruistic donors are motivated to donate for many different reasons.
- All altruistic donors undergo a mental health assessment, as per UK guidelines.
- Potential altruistic donors can be referred directly to the transplant teams.

Sarah Lundie
Living Donor Transplant Co-ordinator,
Royal Infirmary of Edinburgh

Donor for Paediatric Recipient

The Paediatric Transplant Service for Scotland is managed by the team at the Royal Hospital for Children in Glasgow.

All potential donors in Scotland will be referred to the Living Donor Transplant Co-ordinators at the Queen Elizabeth University Hospital (QEUH) via the Paediatric Transplant Service, regardless of where they live.

The paediatric link at the QEUH will then ensure that any potential donors are referred on to their local centres where possible for initial assessment and they will continue to coordinate the process with the local team.

The paediatric link will work closely with the Paediatric Transplant Service to ensure the smooth planning of the transplant for the child and will feed back to the monthly Multi-Disciplinary Team meeting. Donor work-up follows the same pathway regardless of whether the intended recipient is an adult or child.

The donor operation takes place at the QEUH, with the paediatric recipient at the adjoining Royal Hospital for Children in Glasgow. Arrangements for the donor visiting the recipient are made as soon as the donor is able to mobilise.

Key Information

- Siblings aged less than **18 years** would not be considered for donation.
- The living donor transplant co-ordinator at the QEUH co-ordinates the donor process.

Loraine Lawson
Transplant Co-ordinator,
Queen Elizabeth University
Hospital, Glasgow

Mythbusting

The donor is likely to end up on dialysis because they have only one kidney.

No: The risk of a donor developing end stage renal failure is very low 0.1 to 1 in 100.

The donor requires to be blood group compatible with the recipient.

No: Donor and recipient can enter the UK Kidney Sharing Scheme or explore direct donation with antibody reduction treatment.

A number of religions do not allow kidney donation.

No: All major religions support living donation.

There is an upper age limit for living donors.

No: Some older donors may require extra tests pending past medical history, but there is not an upper age limit.

The recipient has their own kidneys taken out before or during the transplant.

No: In most cases the recipients' own kidneys are left in situ and the new kidney is transplanted above the groin.

A kidney transplant will last forever.

No: A transplant is a treatment, not a cure, however kidney transplants from a living donors are very successful, with over 80% of transplants still functioning at 10 years.

Donors who live abroad or other areas of the UK have to come to the recipient centre for their assessment.

No: The living donor team will liaise with the donor's nearest centre for testing.

Once a donor has offered, they are committed to donating?

No: The donor is given the opportunity at every stage to withdraw.

Donors can get paid for donating a kidney?

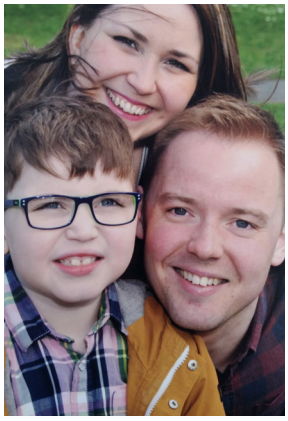
No: This is illegal. However reasonable loss of earnings and legitimate travel expenses can be reimbursed on request. (See further info on pages 24 & 25)

The donor requires to be related to the recipient to be a 'good match'.

No: Many living donor transplants are between pairs who are not related. See page 8 for further information.

ROSS AND FINLAY'S STORY

Finlay was 3 years old when he was diagnosed with chronic kidney disease. It was discovered purely by chance as blood tests testing for developmental disorders showed up high levels of waste products in his blood.



Finlay, Ross and Jennifer

It was an upsetting time and a shock for the whole family as there had been no sign of kidney disease. We were advised that he would need a kidney transplant probably by the time he was a teenager. However, Finlay's kidneys had other ideas and he went into end stage renal failure when he was 5 years old.

Finlay had peritoneal dialysis 7 nights a week for 10 hours overnight. Ross and his wife were tested to see if we were able to be the donor. They were both a match however Ross was the better match.

The day finally arrived for the operations and Ross went to theatre in the morning in the adult hospital and Finlay late morning in the children's hospital in Glasgow. The transplant was a success and Finlay's new kidney was working well and continues to work well.

Ross said:

"The biggest difference I have seen in Finlay is his energy levels. He can walk and even run now. We both recovered quickly from the operations and for the first time in years we enjoyed holidays abroad. Finlay loves swimming and without his dialysis tube holding him back, there is no stopping him!"

Paediatric Recipient Care

All renal transplants in children and young people under 16 years of age take place in Glasgow, with the children being looked after at the Royal Hospital for Children (RHC) and the adult donor being managed in the Queen Elizabeth University Hospital (QEUH).

Parents will often ask about the possibility of being donors early in the course of a child's illness. Checking blood groups and a general health screen is the first step. See page 16 for donor information.

Consideration also needs to be given to the rest of the family, in particular who care for siblings during the time of transplantation, during what might be a prolonged spell away from home for families living outwith Glasgow.

Paediatric recipients are usually in hospital for 10-14 days, but occasionally admissions can be longer. Blood tests are checked regularly during the first few weeks after a transplant and some of these need to be in Glasgow. So whilst the child may be at home by this time, they will require regular trips to Glasgow at a time when one parent may be recovering post op. Accommodation can be arranged in Glasgow for those living a considerable distance from Glasgow.

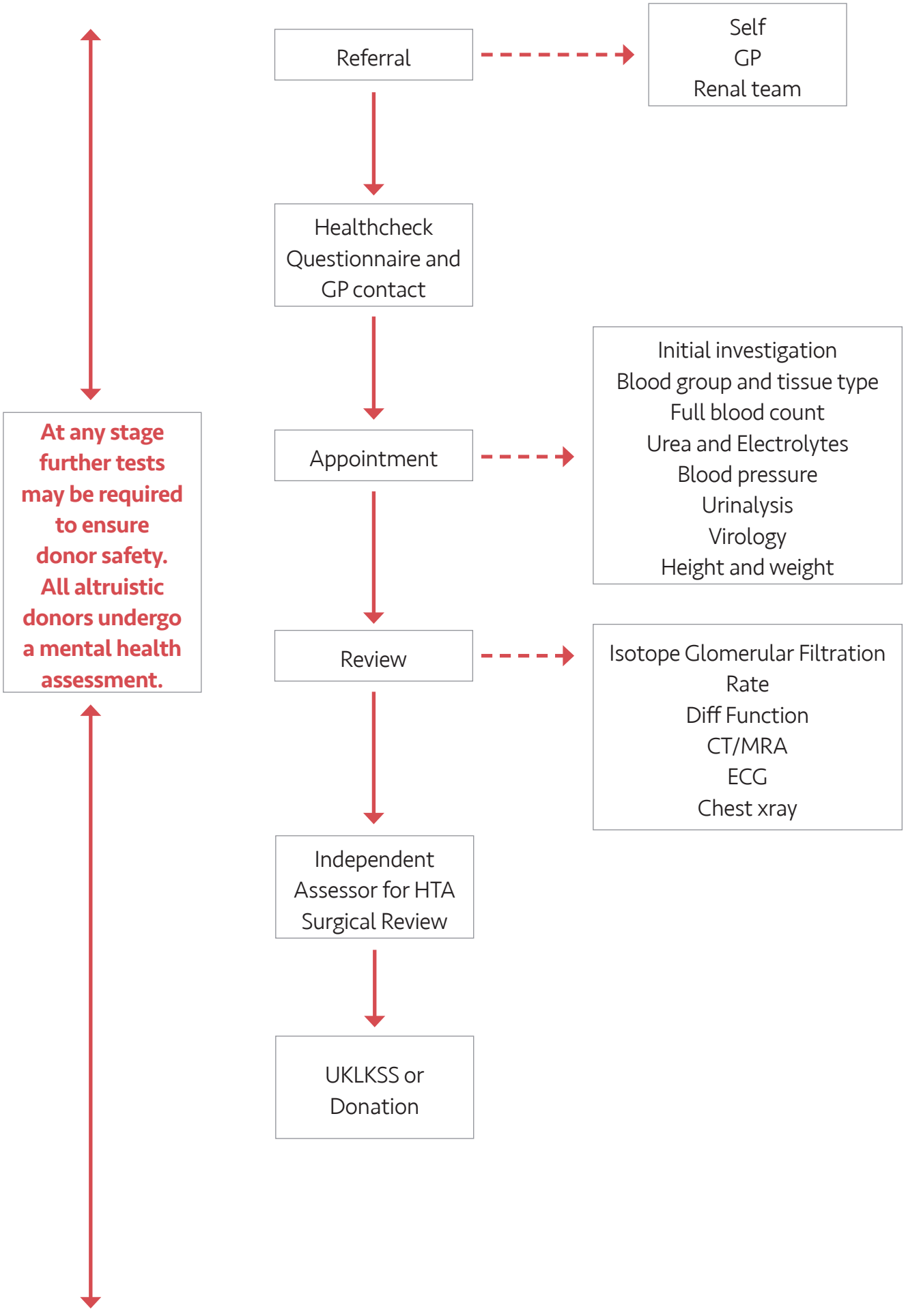
Post-transplant care will be shared with local paediatricians as soon as is deemed appropriate, in conjunction with the transplant team in the RHC. Most children will have an internal J-J ureteral stent in situ post-transplant which will be removed under general anaesthetic after 4-8 weeks. This will usually take place in the RHC. Haemodialysis lines or peritoneal catheters can also be removed at this time.

Key Information

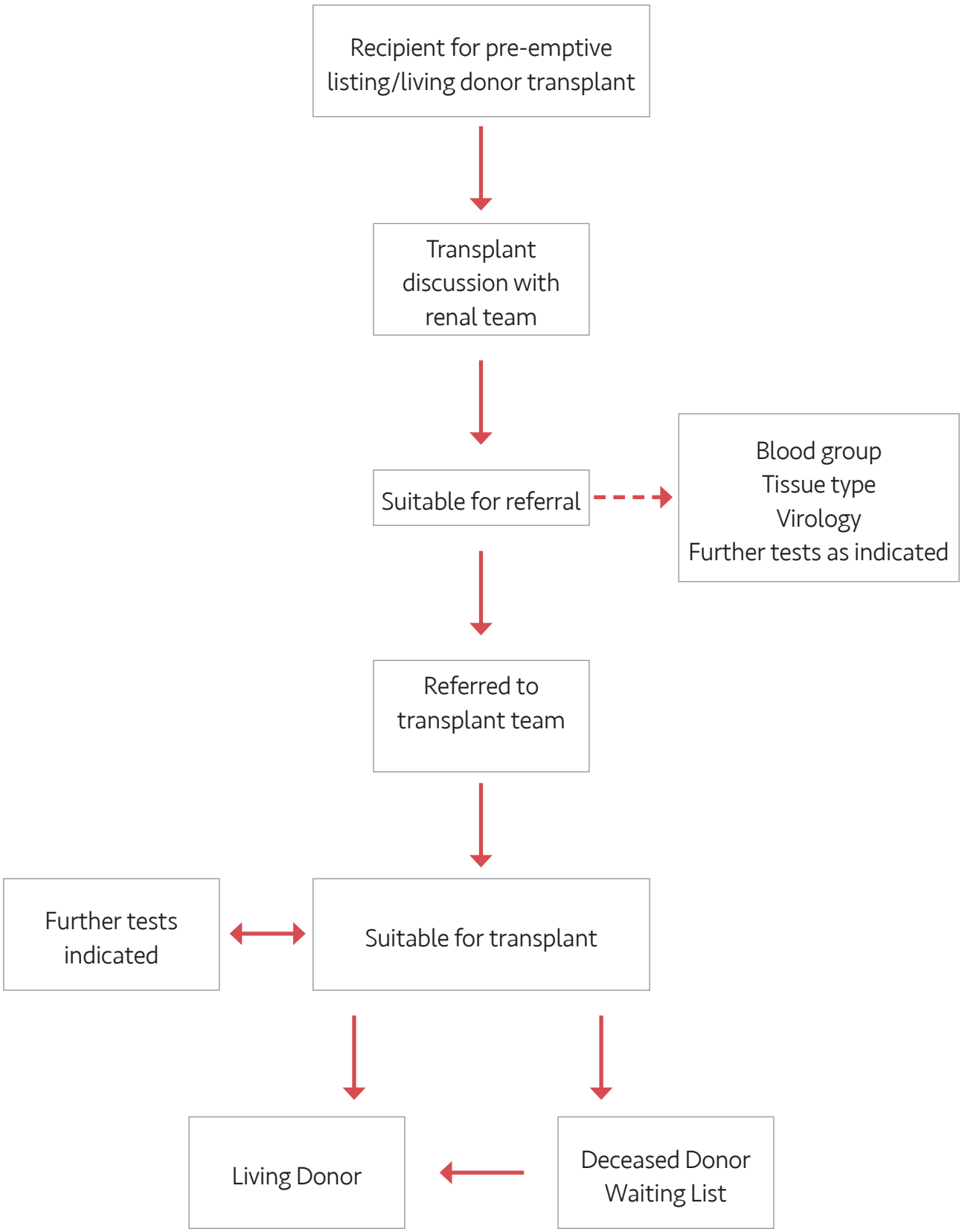
- Some **16-18 year olds** are also managed within paediatric services. There are between 8-12 paediatric kidney transplants per year in Scotland.
- Renal transplantation becomes possible for children with chronic kidney disease once they reach **12kg in weight**, which is usually about **2-3 years of age**.
- Between **50-60%** of transplants in children are from living donors; even very young children can receive an adult sized kidney.
- Approximately **35-45%** of transplants are pre-emptive. Children grow and feel better with a transplant than when they are on dialysis, so time spent on dialysis is kept to a minimum.
- Paediatric recipients are usually in hospital for **10-14 days** but occasionally admissions can be longer.

Dr Heather Maxwell
Consultant Paediatric Nephrologist
Royal Hospital for Children, Glasgow

Donor Flow Chart



Recipient Flow Chart



Glossary of Terms

Deceased donor	A person who donates their organs or tissue for transplantation after their death.
Dialysis treatment	A treatment for people with kidney disease which filters their blood to remove harmful waste, extra salt and water when their kidneys are not able to do this.
HLA-Type	Proteins known as Human Lymphocyte Antigens (HLA) make up the individual HLA-type of every person. This is often referred to as tissue-type. This can be thought of as a 'bar code' which is on the surface of cells. Unless you have an identical twin, then nobody else has exactly the same 'bar code' as you, but it is helpful in transplantation if the donor has similar 'bar code lines' to you. The HLA-type helps to identify suitable donors for recipients.
HTA Human Tissue Authority	The HTA is the regulatory body set up to implement the requirements of the Human Tissue Act and the Human Tissue (Scotland) Act in relation to living donors. It regulates the donation of organs from living people in the UK. All donors are required to meet an Independent Assessor who is trained and accredited by the HTA. The Independent Assessor ensures the donor has capacity to consent to the procedure, is not under any pressure to donate and that no reward is being given. In the case of directed donation or pairs entering the kidney sharing scheme, the Independent Assessor meets both donor and recipient.
Living Donor Transplant Co-ordinator	A specialist nurse who is the main point of contact and guide throughout the donation process.
Living kidney donor	A person who donates one of their healthy kidneys for transplantation whilst alive.
Non-directed altruistic donor	A person who donates one of their healthy kidneys for transplantation whilst alive, but to someone they do not know.
Pre-emptive living donor transplantation	The circumstances when someone has a kidney transplant prior to going on dialysis.
Recipient	A person with kidney disease who receives a kidney transplant.
UK Living Kidney Sharing Scheme	The UK Living Kidney Sharing Scheme (UKLKSS) is a UK-wide kidney exchange programme in which donor and recipient pairs who are incompatible by blood group or human leucocyte antigen (HLA) type can participate to achieve a compatible or better matched transplant with a greater chance of a successful outcome.

Acknowledgements

Thank you to the following individuals who contributed to this resource pack:

Mr Gabriel Oniscu
Consultant Transplant Surgeon, Royal Infirmary of Edinburgh

Dr Colin Geddes
Consultant Nephrologist, Queen Elizabeth University Hospital, Glasgow

Dr Paul Phelan
Consultant Nephrologist and Renal Transplant Physician, Royal Infirmary of Edinburgh

Mr Marc Clancy
Consultant Surgeon and Clinical Lead for Transplantation, Queen Elizabeth University Hospital, Glasgow

Professor Lorna Marson
Consultant Transplant Surgeon, Royal Infirmary of Edinburgh

Dr David Walbaum
Consultant Nephrologist, Aberdeen Royal Infirmary

Dr Heather Maxwell
Consultant Paediatric Nephrologist, Royal Hospital for Children, Glasgow

Dr David Turner
Consultant H&I, Scottish National Blood Transfusion Service

Lisa Burnapp
Lead Nurse for Living Donation, NHS Blood and Transplant

Julie Glen
Living Donor Transplant Co-ordinator, Queen Elizabeth University Hospital, Glasgow

Loraine Lawson
Transplant Co-ordinator, Queen Elizabeth University Hospital, Glasgow

Sarah Lundie
Living Donor Transplant Co-ordinator, Royal Infirmary of Edinburgh

Jen Lumsdaine
Living Donor Transplant Co-ordinator, Living Donation Scotland Project, Royal Infirmary of Edinburgh

Linda White
Policy Manager, Organ and Tissue Donation and Transplantation Scottish Government

Thanks also to the NHSScotland link nurses for their contribution to this pack and to the Scottish Renal Registry for use of their Scotland map.

Money Matters

(Information for potential donors)

There is a lot to consider when thinking about donating a kidney, and quite often people are worried about time off work and their pay. Most employers will provide sick pay, but in some circumstances, such as being self-employed, this may not be possible.

Donors should be no worse off as a result of donating and so they can apply for money to cover their lost earnings and expenses. However, it is illegal for anyone in Scotland or the rest of the UK to be paid to donate and so the donor cannot profit in any way.

What you need to do

- It is the responsibility of the donor to complete the claim form and provide full evidence and receipts.
- It is important to contact your Living Donor Transplant Co-ordinator at an early stage in your assessment to start the claim form process.

The living donor is entitled to claim:

Travel expenses

- Travel expenses can only be reimbursed to the donor (not the recipient or any family members travelling with them).
- The cheapest and/or most appropriate mode of public transport must be used.
- Tickets/receipts to support the claim for expenses are required.
- Mileage will be at the agreed standard NHS rate set at a level not lower than the advisory fuel rates specified by HM Revenue & Customs.
- Taxi fares will only be reimbursed if clinically necessary and approved by the clinical team.

Accommodation expenses

- Accommodation costs can only be reimbursed to the donor.
- An overnight stay in a hotel, guesthouse or other accommodation must be agreed in advance with the clinical team up to the normal maximum NHS limit in order for costs to be reimbursed.
- Receipts to support the claim for accommodation are required.

Payment for loss of earnings

- If you lose money due to not being paid while you are off work, you can claim money to cover your lost earnings (up to certain limits). Tax liability or changes to benefit entitlement depends on the employment status of the individual. The Living Donor Transplant Co-ordinator may refer you to the Social Work Team.
- Loss of earnings are paid up to 8 weeks post donation for the first claim, and approval for a further 4 weeks can be made after the 6 week post-donation review.
- You must provide the previous 6 months payslips and further information may be required from your bank.
- Your P60 may be required for overtime patterns and pay from the previous year.
- For employed donors – reimbursement is paid of net income and will not be taxable. Some employers may continue to pay basic pay, but the donor may lose supplementary pay in the form of commission or tips. Such losses may be reimbursed on provision of suitable proof of average overall earnings.
- For self-employed donors – reimbursement for self-employed donors is based on gross income and as such will be liable to tax. Selfemployed donors should provide proof of lost gross income through documentation such as a copy of their latest tax return, as well as bank statements covering the period affected and a comparative period from the previous year.
- You must provide evidence of statutory sick pay (SSP) and may be entitled to top-up if SSP is lower than your salary.

Miscellaneous expenses

- Claims for the reimbursement of additional expenses such as child care costs, additional accommodation, etc. will be considered on an individual basis. Documentation to support the claim for these expenses must be provided.
- Subsistence costs for meals and drinks will not be reimbursed.
- Potential donors who are deemed unsuitable to proceed to donation may be eligible to claim for reimbursement of certain expenses incurred during their assessment, such as travel expenses, including parking costs.

Completed claim forms with supporting documents should be submitted before the operation

Living Kidney Donor Contacts

This section provides a general overview of pathway and referral in Scotland, and can be adapted for individuals. Please note contact details and pathways do change, refer to www.livingdonationscotland.org for updates and more detailed information.

Hospital	Pathway Overview	Transplant Referral	Contact
Aberdeen Royal Infirmary 	Potential donors from Aberdeenshire, Moray, Orkney and Shetland come to Aberdeen Royal Infirmary for their assessment.	The Edinburgh Transplant Centre	Renal Unit Aberdeen Royal Infirmary Foresterhill Aberdeen, AB25 2ZN Tel: 01224 559 497 Email: **nhsg.livedonation@nhs.net**
University Hospital Crosshouse 	Potential donors from Ayrshire and Arran come to Crosshouse Hospital for their initial assessment, with radiological tests completed in the Queen Elizabeth University Hospital, Glasgow.	Queen Elizabeth University Hospital, Glasgow	Renal Transplant Co-ordinator John Lynch Renal Unit University Hospital Crosshouse Kilmarnock Road Crosshouse KA2 0BE Tel: 01563 825080 Email: **aa-uhb.clinical_renaltransplant@nhs.net**
Dumfries and Galloway Royal Infirmary 	Potential donors from Dumfries and Galloway come to Dumfries and Galloway Royal Infirmary for their assessment.	Queen Elizabeth University Hospital	Renal Unit Mountainhall Treatment Centre Bankend Road Dumfries, DG1 4AP Tel: 01387241079 Email: **robert.mclemon@nhs.net**
Fife Hospitals 	Potential donors from Fife contact the transplant co-ordinator at Fife Hospitals	The Edinburgh Transplant Centre	Renal Unit Victoria Hospital Hayfield Road Kirkcaldy, KY2 5AH Email: **fife-uhb.fiferenaltransplant@nhs.net** Tel: 01592643355 Ext 20176
Forth Valley Hospital 	Potential donors from Forth Valley come to the Queen Elizabeth University Hospital for their assessment.	Queen Elizabeth University Hospital, Glasgow	Living Donor Transplant Co-ordinators Office Block, 1st floor zone 3 Queen Elizabeth University Hospital 1345 Govan Road Glasgow, G51 4TF Email: **gg-uhb.renallivedonorteam@nhs.net** Tel: 0141 451 6200

University Hospital, Monklands 	Potential donors from Lanarkshire come to Monklands Hospital for their initial assessment with radiological tests completed in the Queen Elizabeth University Hospital, Glasgow.	Queen Elizabeth University Hospital, Glasgow.	Renal Unit Monklands Hospital Monkscourt Avenue Airdrie, ML6 0JS Email: **donatelanarkshire@nhs.net** Tel 01236 712 648
Ninewells Hospital, Dundee 	Potential donors from Tayside, Perth and North Fife come to Ninewells Hospital for their assessment.	The Edinburgh Transplant Centre	Renal Unit Ninewells Hospital James Arnott Drive Dundee, DD1 9SY Email: **irene.russell@nhs.net** Tel 01382 633 897
Raigmore Hospital, Inverness 	Potential donors from the Highlands and Islands come to Raigmore Hospital for their assessment.	The Edinburgh Transplant Centre	Renal Unit Raigmore Hospital Old Perth Road Inverness, IV2 3UJ Email: **lynda.maclean@nhs.net** Tel 01463 706689
The Edinburgh Transplant Centre 	Potential donors from Lothian and Borders come to the Royal Infirmary of Edinburgh for their assessment. Referrals from Fife, Tayside and Perth, Highlands and Western Isles, Grampian, Orkney and Shetland for review and donation		Living Donor Transplant Co-ordinators The Edinburgh Transplant Centre Royal Infirmary of Edinburgh Old Dalkeith Road Edinburgh, EH16 4SU Email: **lothian.livingkidneydonation@nhs.net** Tel: 0131 242 1703 Web: www.edinburghtransplant.org
Queen Elizabeth University Hospital 	Potential donors from Greater Glasgow and Clyde, and Forth Valley come to the Queen Elizabeth University Hospital for their assessment. Referrals from Lanarkshire, Ayrshire and Arran, Dumfries and Galloway for review and donation		Living Donor Transplant Co-ordinators Office Block, 1st floor zone 3 Queen Elizabeth University Hospital 1345 Govan Road Glasgow, G51 4TF Email: **gg-uhb.renallivedonorteam@nhs.net** Tel: 0141 451 6200

Where can I find out more information and advice on living kidney donation?

Visit: livingdonationscotland.org

Email: livingdonationscotland@nhs.net

Call: Contact the Living Donor Transplant Co-ordinator at your nearest Transplant Unit on: Edinburgh 0131 242 1703 Glasgow 0141 451 6200

Living Kidney Donation Contacts

Hospital	Tel No
Aberdeen Royal Infirmary	01224 559 497
University Hospital Crosshouse	01563 825080
Dumfries and Galloway Royal Infirmary	01387241079
Fife Hospitals	01592643355 Ext 20176
University Hospital Monklands	01236 712 648
Ninewells Hospital Dundee	01382 633 897
Raigmore Hospital Inverness	01463 706689
Transplant Units	
Edinburgh Transplant Centre	0131 242 1703
Queen Elizabeth University Hospital Glasgow	0141 451 6200

LIVING KIDNEY **DONATION**

The Exceptional Gift

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Scottish Government