

LIVING
KIDNEY
DONATION

The
Exceptional
Gift

Living Donor Kidney Transplantation

“
Thank you will never be
enough. I have a family
and a future and will be
forever grateful.

Julie, Kidney Recipient
”



Healthier
Scotland
Scottish
Government

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The Exceptional Gift

Why living kidney donation?

Living donor kidney transplantation is the most effective treatment for many people with end-stage kidney disease. Living donation allows the surgery to be planned at a convenient time for everyone involved and can enable recipients (patients with end-stage kidney disease) to avoid dialysis entirely, and can offer very good long term outcomes.

A kidney will never be removed from a living donor until the team are satisfied that the short and long term risks to that person are low. All risks are explained in detail during the donor assessment.

Why more donors are needed

Many people wait an average of three years or more as there are not enough available kidneys from deceased donors. For some ethnic groups or individuals with rare tissue types or higher antibody levels, the wait can be significantly longer. A kidney transplant improves life expectancy for kidney failure patients compared to dialysis.

Becoming a living kidney donor

Healthy adults who wish to help a loved one, friend, or someone whom they do not know on the national waiting list may volunteer to donate. Donor safety is always the priority and not everyone who wishes to donate will be suitable. Each donor is assessed to ensure minimum risk.

Each donor is supported by a Living Donor Coordinator/Specialist nurse, who guides them through the entire process.

Assessment

There is no maximum age limit for donation. Each donor is assessed on their own health and the suitability of the kidney for the intended recipient. In the UK, there have been successful living kidney donations from people over 80 years of age.

Assessment includes medical tests such as blood and urine tests, scans, heart tracing, x-rays and kidney function testing. A psychological assessment may also be required. Further investigations may be requested if the routine tests are not satisfactory.

Not all donors who come forward can proceed to donation, depending on the outcome of the investigations. The living donor team are there to support donors through these decisions and referral for a second opinion can be requested.

For directed donation, all donors and recipients must meet with an Independent Assessor, who ensures understanding of the process and confirmation that the donor is not under pressure or receiving payment. The Independent Assessor acts on behalf of the Human Tissue Authority who are required to provide legal approval for the living donor transplant. In the case of non-directed altruistic donation it is only the donor who is interviewed by the Independent Assessor.

Risks and long term considerations

As with any major surgery, donating a kidney carries risks, including infection, bleeding, or blood clots. Serious complications are rare but can never be excluded, and risks will be fully discussed with you.

Most donors live long, healthy lives with one kidney. Some may develop slightly higher blood pressure or small amounts of protein in the urine, but these can be monitored and treated. All donors are encouraged to attend an annual review appointment to monitor blood pressure and kidney function.

Donating to a child

Alongside parents, other adults are often considered including grandparents, aunts and uncles, and close family and friends. Children can also enter the UK Living Kidney Sharing Scheme with their adult donor.

Donor surgery always occurs in an adult transplant centre, which may be separate from the child's hospital.

Surgery and recovery

Kidneys are usually removed using keyhole (laparoscopic) surgery. Very occasionally open surgery is required. The operation takes two to three hours, followed by a short hospital stay of two to four days. Pain relief is provided throughout recovery. Donors generally return to normal activities within several weeks.

Practical considerations

Insurance

Donors should check their cover before proceeding.

Travel and location

Assessment can often be arranged locally, even if the donation occurs elsewhere.

Time off work

Recovery time varies depending on the nature of your job, though is usually around 6 to 12 weeks.

Expenses

In Scotland, donors may reclaim necessary expenses, including loss of earnings and travel (see page 8).



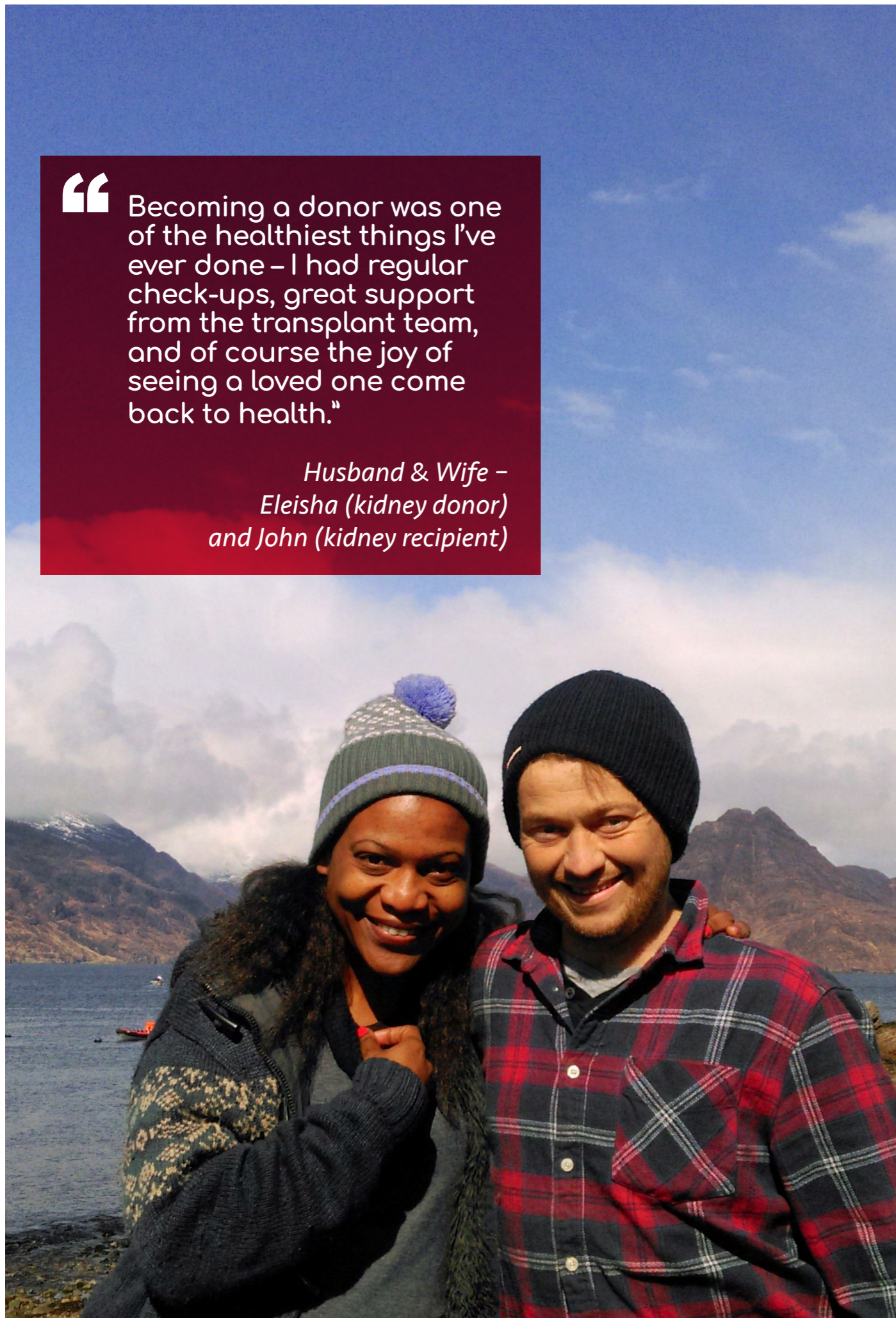
“Living kidney donation is an extraordinary gift, and anyone can volunteer to find out more about donating.”

Linda



Becoming a donor was one of the healthiest things I've ever done – I had regular check-ups, great support from the transplant team, and of course the joy of seeing a loved one come back to health.”

*Husband & Wife –
Eleisha (kidney donor)
and John (kidney recipient)*



Cultural and religious perspectives

Most cultures and religions view living kidney donation positively. If you are unsure, you may wish to discuss this with your community or faith leader.

Decision making

Deciding to donate is personal and it is normal to have mixed feelings. You may withdraw at any time, and your living donor team will support your decision. Speaking with someone who has donated may help; your coordinator can arrange this.

Success rates

Living donor kidney transplantation is highly successful, with 96% of kidneys functioning well one year after surgery. Although most transplants are successful, complications can occur, and some kidneys may fail. It is important to consider how you would feel if the transplant does not work as expected.

Next steps

If you are considering donating to someone you know, contact their transplant centre. If you are interested in non-directed altruistic donation, [contact your local transplant centre's living donor team](#).

Telephone the transplant centre

Edinburgh 0131 242 1703

Glasgow 0141 451 6200

Visit: www.livingdonation.scot



Common questions asked by donors

Do donors need to be related to the recipient to be a 'good match'?

No, many living donor transplants are between pairs who are not related.

Do donors who live abroad or other areas of the UK have to come to the recipient centre for their assessment?

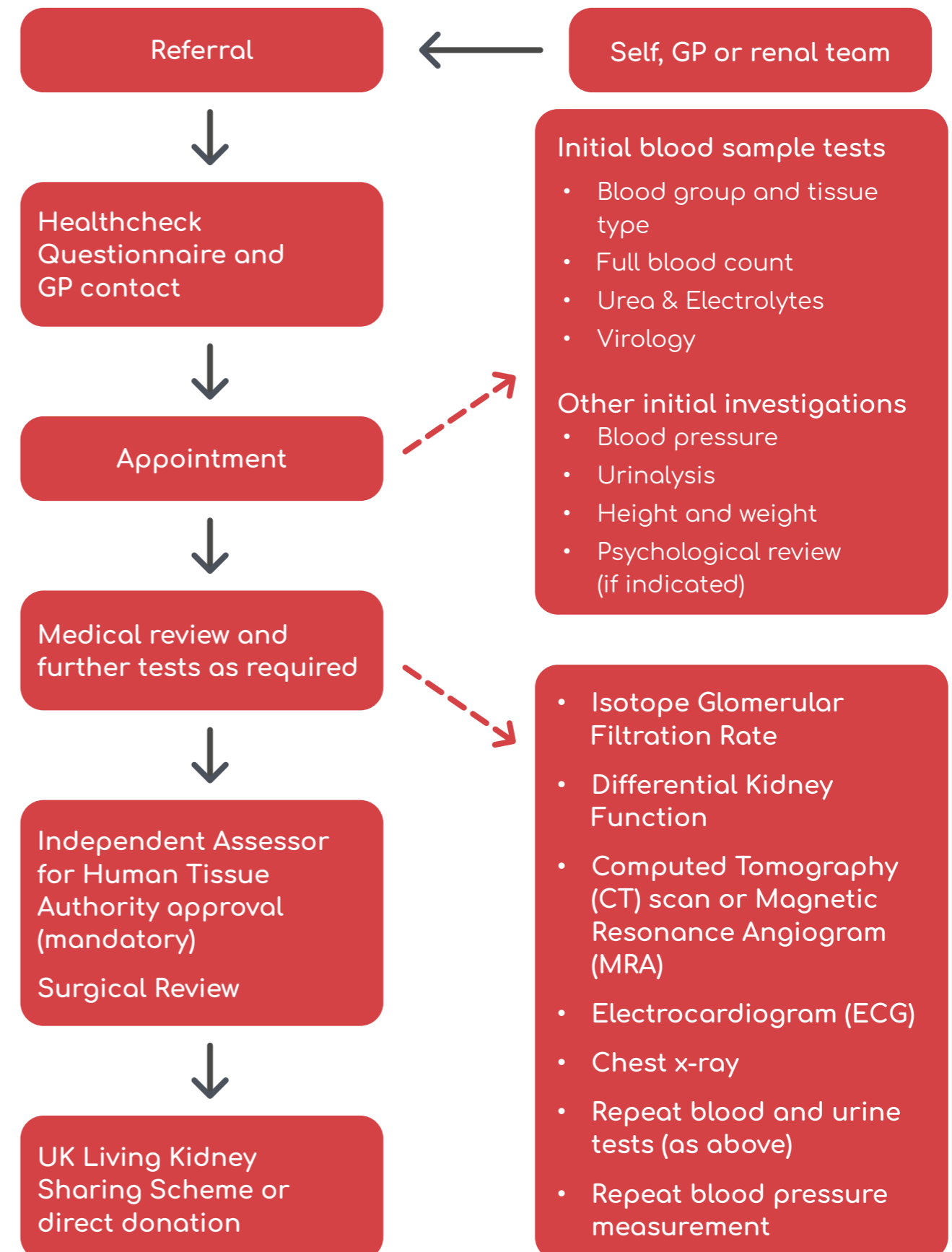
No, the living donor team will liaise with the donor's nearest centre for testing; however, the donation and transplant is likely to take place at the recipient centre.

Do all religious groups allow kidney donation?

Yes, all major religions support living donation.

Donor flowchart

Each potential donor is assessed according to their current and past medical history. This flowchart represents some of the routine donor tests to assess physical and mental health. The tests and reviews will vary depending on the transplant centre protocols.



“ The feeling that I had not been expecting was the sense of wellbeing after I donated, knowing I had transformed another person's life and their future.

John, Kidney Donor

Money matters – living kidney donor reimbursement

Considering living kidney donation involves many factors, including time away from work and potential loss of income. While most employers offer sick pay, this may not apply to everyone, such as those who are self employed.

Living donors should not be financially disadvantaged. They may apply for reimbursement of lost earnings and eligible expenses. However, it is illegal across Scotland and the UK for donors to receive payment for donating an organ, and donors must not profit in any way.

Donors are responsible for completing the claim form and providing all required supporting evidence. Please contact your Living Donor Transplant Coordinator early in your assessment to begin this process.

What you can claim

Travel expenses

- Travel costs for the donor only (not for recipients or accompanying family members)
- The cheapest or most appropriate public transport should be used
- Tickets/receipts must be provided
- Mileage is reimbursed at the standard NHS rate
- Taxi fares require prior clinical approval and must be clinically justified

Accommodation

- Accommodation costs for the donor may be reimbursed if agreed in advance with the clinical team
- Reimbursement is limited to standard NHS maximum rates
- Receipts are required

Loss of earnings

If you lose income because you are not paid while off work, you may claim reimbursement within reasonable limits. Tax implications vary depending on employment status. You may be referred to the social work team for further advice.

You must provide:

- The previous six months of pay slips
- Bank statements (if requested)
- Your P60 (if required to confirm overtime patterns or previous earnings)
- Evidence of Statutory Sick Pay (SSP)

For employed donors

Reimbursement is based on net income and is not taxable. Employers may continue basic pay but exclude supplementary earnings (e.g., commission, tips). These may be reimbursed with sufficient evidence.

For self employed donors

Reimbursement is based on gross income and will be subject to tax. You must provide proof of lost income such as a recent tax return, bank statements for the affected period, and a comparative period from the previous year.

Miscellaneous expenses

Additional reasonable costs, such as childcare or extra accommodation, may be considered on an individual basis. Supporting documentation is required.

Potential donors who are found unsuitable may claim reimbursement for some assessment-related expenses, such as travel and parking.

Social media appeal

Some people who are waiting on a kidney transplant use social media to raise awareness.

Here are a few helpful tips if you are considering this:

- First speak to your local Living Donor Coordinator and tell them of your intention, they can help you find the words and ensure you post the correct contact details.
- Think about what detail you want to go into about your illness: once something has been posted over the internet, it will always be there!
- Be aware – not everyone’s comments will be supportive and some may even be hurtful.
- Members of the transplant team should never be named in person. Do not post your own contact details.
- Remember you may get 10s, 100s, 1000s or no ‘likes’. This does not mean you will find a donor.
- The donor assessment process has to be donor driven. Ask any potential donor to contact their local Living Donor Coordinator/Specialist nurse directly for further guidance.

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

Visit: livingdonation.scot



UK Living Kidney Sharing Scheme

It is important that both donors and recipients are aware that they do not need to be a ‘good match’ for the transplant to proceed. The UK Living Kidney Sharing Scheme (UKLKSS) is a UK wide programme started in 2007 that helps recipients who have a suitable living kidney donor but they are not compatible or not a good match. By joining the scheme, donor–recipient pairs can be matched with other pairs in a similar situation, allowing recipients to receive a suitable kidney.

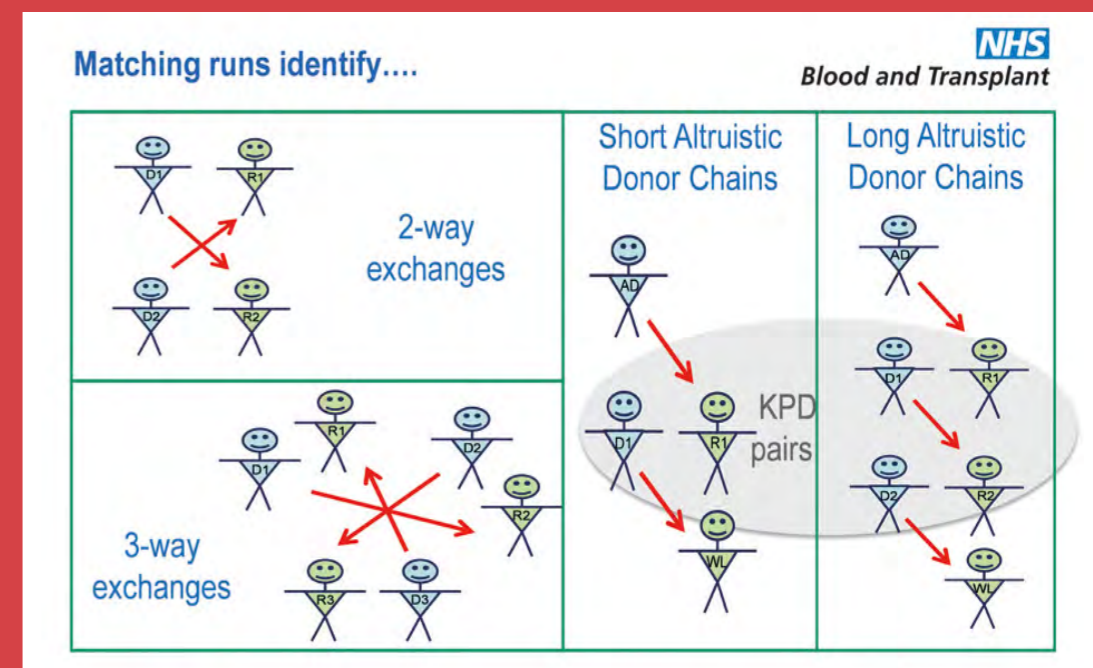
Who can join the scheme?

- Pairs who are incompatible because of blood group or tissue type.
- Pairs who are compatible, who are looking for a different match.
- Non-directed altruistic donors, who choose to donate a kidney anonymously, are also included and may start a chain of transplants helping several people.

How does it work?

Every three months, NHS Blood and Transplant performs a matching run with all registered pairs and donors to find the best possible matches.

- Most donors and recipients stay at their own transplant centre.
- Kidneys are transported between centres when needed.
- Whenever possible, donor operations are carried out at the same time to ensure fairness and safety.



How long does it take?

Surgery is usually planned within eight weeks of a match being found. Your living donor transplant team will guide you through the timetable, tests, and next steps.

Information for potential recipients

When you are told that you need a kidney transplant, it can feel overwhelming, and starting conversations with family or friends about living kidney donation may be difficult. Many people are unsure what to say or how to approach the subject. Overall a kidney from a living donor offers better long term outcomes, and those close to you may find it helpful to know this when thinking about how they can support you.

Healthcare professionals are available to help you share information with those around you. Specialist nurses visit you at home to speak with you and your family and friends about transplantation – ask your local unit about a REACH Transplant visit. It is also helpful to bring someone with you to your outpatient appointments. There is often a lot to take in, and having support can make it easier to remember details and explain things later.

- Potential donors must approach the renal or transplant team themselves. The recipient cannot make this contact on their behalf. This ensures that anyone wishing to donate does so voluntarily and has the opportunity to ask questions privately.
- The donor assessment process usually takes three to six months, although this can vary. A recipient can feel this period frustrating, especially if someone you know is keen to donate. The timeline depends on medical assessments, test results, and scheduling.
- Donor assessments are carried out separately from recipient care. This is to protect the donor's privacy, health, and wellbeing. Their results and discussions with the clinical team are shared directly with them. Recipients cannot have access to a donor's test results or details of the donor assessment outcome.
- Many people find it helpful to speak with other transplant recipients about the emotions and concerns that can arise when accepting a kidney from someone you know. Your specialist team can help put you in touch with others who have been through the process and can share their experiences.



“ Being a living donor is one of the most rewarding things you can do - we joined the UK Living Kidney Sharing Scheme where David donated his kidney to a stranger and I received one from another donor which has given me the chance to live well again..”

*Husband & Wife –
David (kidney donor)
and Rachel (kidney recipient)*

“ I received a living donor kidney transplant from my stepmother. I am so grateful to her and all the hospital staff for giving me my life back. It is an amazing thing these people do and it makes such a difference.”

Julie, Kidney Recipient



Common questions asked by recipients

How do I raise the subject with friends and family?

We know it can be a difficult subject to raise. The best way is to give everyone the facts: you need a transplant and a kidney from a living donor is your best option. Explain what you know about life on dialysis and the improved life expectancy with a kidney from a living donor.

If they would like to know more they can visit livingdonation.scot, which will give them more information on the process and exactly what is involved.

I think my potential donor is too old.

There is no upper age limit to being a living donor – everyone is assessed as an individual.

Every potential donor that comes forward undergoes a number of standard investigations, and often extra tests, if required. The risks involved are carefully explained to both donor and recipient.

My son and daughter are both keen to donate to me, but I don't want them to take the risk.

This is a common concern from parents or anyone being offered a kidney from a younger person – but please discuss and listen to their views and reasons.

A kidney will never be removed from a living donor until the team are satisfied that the short and long term risks to the donor are low. All risks are explained in detail during the donor assessment.

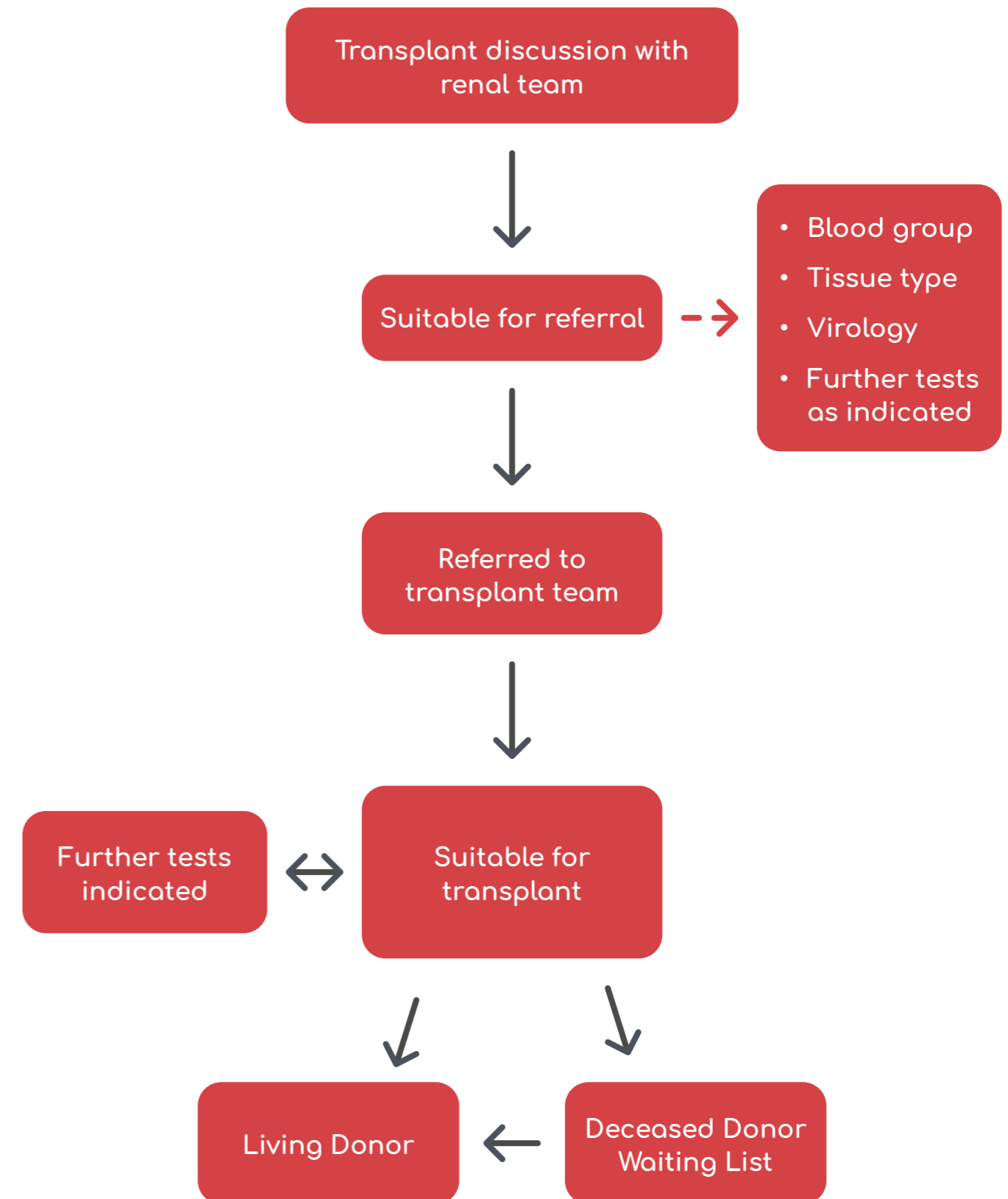
My potential donor is willing to be tested, but we can't afford for them to be off work.

There is a scheme for reimbursement of reasonable expenses relating to living donation, so if the donor does not receive sick pay from work they may be eligible for reimbursement of loss of earnings and other expenses.

Ask your local living donor transplant coordinator or specialist nurse at an early stage in their assessment.

Recipient flow chart

Each potential recipient is assessed according to their current and past medical history. This flowchart represents some of the routine recipient tests. The tests and reviews will vary depending on the transplant centre protocols.





“ For me it was an emotional time because the man I loved was going to undergo an operation to give me back my life. What a fantastic gift.”

Lynn, kidney recipient

Glossary of Terms

End-stage kidney disease

End-stage kidney disease (ESKD) is the most advanced stage of chronic kidney disease, when the kidneys have lost nearly all of their ability to work on their own and kidney transplantation or dialysis is considered as a treatment option.

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.

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 Coordinator

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

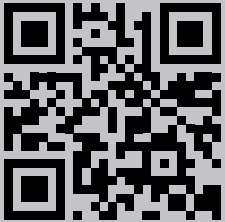
A person with kidney disease who receives a kidney transplant.

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.

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

Visit: livingdonation.scot



Call:

Contact the Living Donor Transplant Coordinator at your nearest Transplant Unit on:

Edinburgh **0131 242 1703**

Glasgow **0141 451 6200**

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