

LIVING
KIDNEY
DONATION

The Exceptional Gift

Information about becoming
a living kidney donor

“

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

”



Healthier
Scotland
Scottish
Government

The Exceptional Gift

Living kidney transplants have been performed in Scotland since 1960, and currently around 100 such operations are performed each year with a very high success rate. A kidney transplant transforms the life of someone with kidney disease, whether they're already having dialysis treatment or not.

Volunteering to offer a kidney is a wonderful thing, whether it's to a loved one/friend or anonymously to someone on the transplant waiting list (altruistic donation). It is, however, a big decision with lots for you to consider. We hope this information will answer some of the questions you may have.

You will find a glossary at the back of this document that will explain some of the more technical terms or abbreviations that are used, just in case these haven't been explained in the text itself.

Why living kidney donation?

- A successful transplant from a living kidney donor can be the best possible treatment for someone with kidney failure, especially if it is scheduled before the recipient needs to start dialysis.
- In general, people who receive a living donor transplant will live longer than those who receive a kidney from a deceased donor.
- 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 we need more living kidney donors

In the past 10 years alone, more than 500 people in Scotland have transformed the lives of others and become living kidney donors. It is possible to live a completely normal life with just one kidney.

- Many are 'directed' donors – nowadays it is often a partner or friend who donates.
- An increasing number of people are offering to be 'altruistic' donors – giving to someone on the transplant list whom they do not know (also known as 'anonymous donation'). An altruistic donor can start a 'chain' of transplants, meaning up to 3 people can receive a transplant in a kidney sharing scheme due to the altruistic donor's gift.
- There are currently more than 5,000 people in the UK on the National Transplant List in need of a kidney. Over 400 of these are in Scotland.



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)*



Donating a kidney

Can I volunteer to be a living kidney donor?

- Yes. Anyone can volunteer to give a kidney. Volunteer is the key word – this must be something that you choose to do and feel comfortable doing.
- If you would like to donate you will be asked to undertake a series of tests so that the medical team can be absolutely sure that you are suitable to donate. The assessment will involve a number of visits to hospital.
- Your health and safety is of primary concern and it is important to be aware from the start that not everyone is suitable and you may find that you are unable to donate.
- There is no upper age limit and everyone is assessed as an individual.

Who can donate?

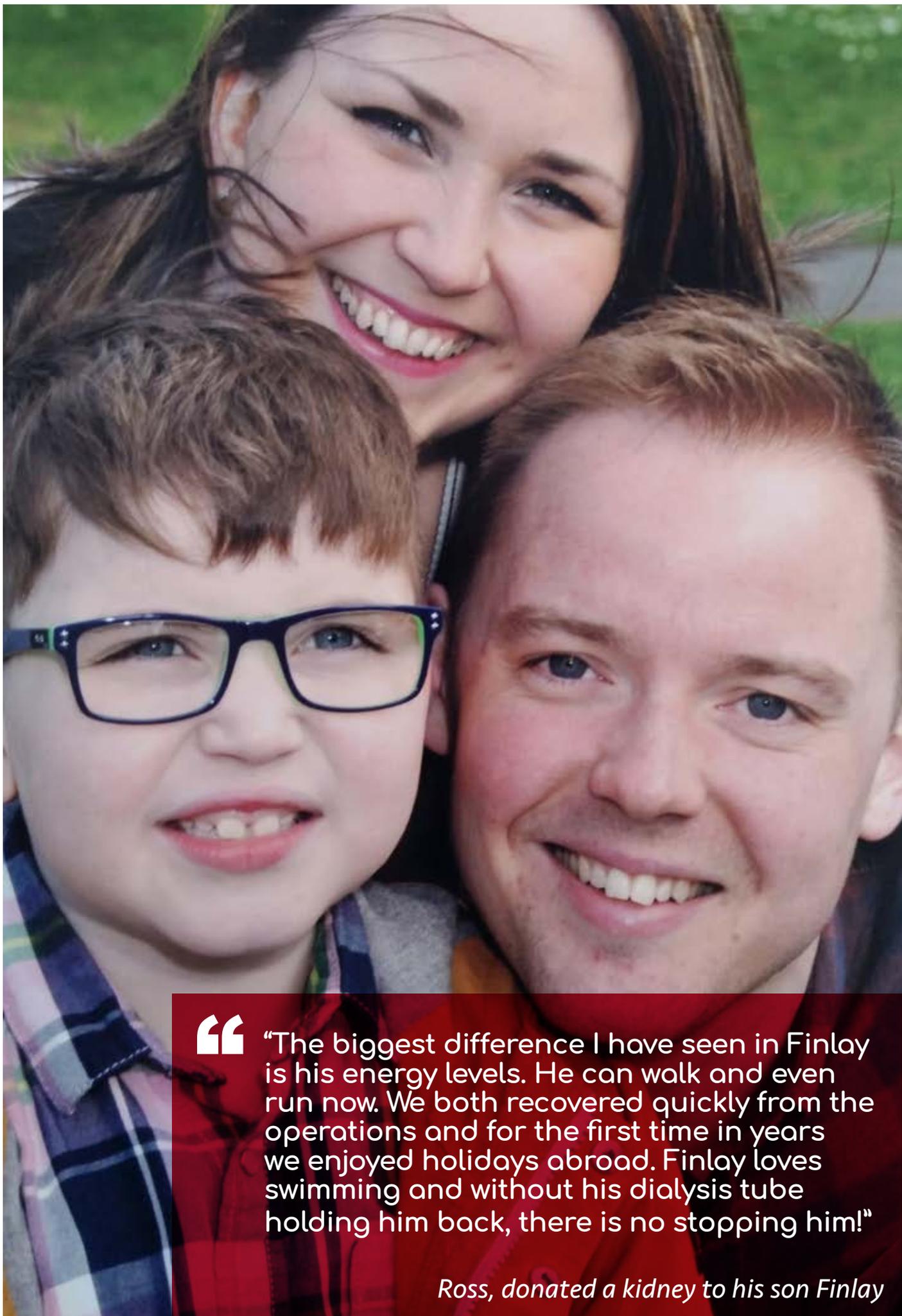
Often donors are close to the recipient, such as a family member, partner or good friend. However, people who don't know anyone with kidney disease, but who wish to donate, can also provide a kidney to someone they don't know on the National Transplant List. This is known as non-directed altruistic donation.

Sometimes a donor and a recipient (who already know each other) may not 'match' with each other because of blood group or tissue type. In some cases, it may be possible for them to be paired with another donor and recipient in the same situation who 'swap' donors. This means that each recipient will benefit from a transplant that they would otherwise not have had. This is called paired donation. Where more than two pairs are involved in the swap it's called pooled donation. A non-directed altruistic donor can also be included in these 'swaps' to enable more transplants to take place. When a non-directed altruistic donor is involved, it is called an altruistic donor chain.

It's important to remember at this stage that if you do choose to become a donor you'll be assigned a Living Donor Transplant Co-ordinator or Specialist Nurse who'll be your main point of contact, and will guide you through every step of the donation process.

Is there an age restriction for donors?

There is no maximum age limit for donation. You are assessed on your 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.



“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!”

Ross, donated a kidney to his son Finlay

How will I know if I am suitable to donate?

You will undergo a number of investigations to check that you are fit and healthy enough to donate. An operation will not go ahead until the doctors are satisfied that any risk to you is acceptably low in both the long and short-term.

Some people who wish to donate find that they're not able to due to results during the assessment process. Members of the team involved in your assessment may include doctors, nurse co-ordinators, counsellors, psychologists and social workers. They will guide you through the process every step of the way.

What are the tests like?

You will be allocated a Living Donor Transplant Co-ordinator who'll guide you through the entire process. They will talk you through all the tests you need to undertake. The tests are there to make sure you're healthy enough to donate and that your kidneys are working properly. They are generally not painful or invasive, but you will be asked for lots of blood samples along the way. The tests include urine tests, blood tests, X-rays and scans (some including an injection), heart tracing (through wires attached to sticky pads on your skin) and a special test of kidney function which involves an injection and a series of blood tests over set time periods.

Your test results will be discussed with you when available. If something unexpected is found then some further tests or assessments may also be needed. It's possible that the tests may show a condition or illness that you didn't already know about. If this is the case, this will be discussed with you and appropriate referrals and treatment provided.

Donors are often asked to have a psychological assessment. This is a meeting with a psychologist or psychiatrist to discuss your personal circumstances, any mental health issues you may have or have had and to explore your understanding of the process and reasons for donating. Donating a kidney can be a very emotional process, and we want to ensure that the risk of any psychological harm to you is acceptably small.

Legally, you must also be assessed by an Independent Assessor on behalf of the Human Tissue Authority, who is completely separate from your medical team. This is a one-to-one meeting at the end of the assessment process, where you'll be asked about your reasons for donating and your understanding of the process. The Independent Assessor checks that you're not being pressurised into donating or being paid to do so, which would be against the law. You will then be asked to sign a declaration. The Human Tissue Authority needs to approve your donation in order for it to go ahead, but in general it's very straightforward and not something you should be anxious about.

The risks

What are the risks for me?

All operations carry some risk and donating a kidney is no different. There is a very small risk of death for the donor: this is estimated at 1 in 3,000 which has been compared to the risk of having a fatal road accident. However, the operation is a common procedure, and the medical team caring for you are aware of the risks and can usually identify and treat these very quickly if they occur.

Most complications are minor and may include infections (e.g. chest, wound or urine) and, rarely, bleeding or blood clots. More serious risks include damage to major blood vessels and organs such as the colon, lungs and spleen which are near to the kidneys, but such complications are rare.

There's also the risk of damage to your emotional well-being or mental health if things don't work out as expected, for example if there are complications for you or the recipient, and particularly if the transplant doesn't work and has to be taken out. For non-directed altruistic donors and donors in the paired/pooled donation scheme, it's likely that you'll never know the outcome of your donated kidney or the identity of the recipient unless the recipient chooses to make contact with you. It can be difficult for some recipients to express how they feel about receiving such a wonderful gift, and many find it hard to put pen to paper to say thank you.

It is important to be prepared for this so that you're not disappointed if you don't hear anything from your recipient. It's very important for you to consider all these things when you're deciding if living donation is right for you, and these will be explained to you as you go through the process.

Are there any long-term risks?

It's possible to live a long and healthy life with one kidney, but obviously donating a kidney does not protect you from other medical problems that you would have developed in any case. Some studies have indicated that there is a slight risk of a small increase in both blood pressure and of protein in your urine as a result of living with one kidney. This is checked at each annual follow-up after donation, and can be treated.

Risk is relative to the person donating and to individual circumstances, and we know that some groups of people may need special consideration. The most important thing is that you understand what the risks are or might be for you before you decide whether or not to donate.

Am I at greater risk of developing kidney failure?

Donating a kidney does not mean that nothing bad will ever happen to you in the future. It's always possible that something unexpected could affect your remaining kidney in years to come. The chances of this, given that you will have had a thorough assessment process before donating, are very low – particularly if you maintain a generally healthy lifestyle after donation. In the unlikely event that you did develop a problem with your kidney, there's a chance that you would require dialysis treatment earlier than if you had both kidneys.

Will it shorten my lifespan?

Studies have shown that donors live longer than other people like them in the general population. This isn't because giving a kidney is good for you, but because those who donate have to be well to begin with and pass a thorough medical assessment. People who have donated also tend to be more aware of leading a healthy lifestyle after donation.

Will I have to change my lifestyle after donating?

No – unless you have unhealthy habits, which you may be advised to change. You should lead a normal, healthy life and be able to do all the activities you can do now.



Donating a kidney to a child

The average waiting time for a kidney transplant (from a deceased donor) for children is between six to twelve months, but for some children the wait can take up to five years. Where a child is involved, living donors are normally a close relative with parents being the most usual donors. Grandparents or siblings can also be considered depending upon their age, and aunts, uncles and other family members or close friends may also be able to donate.

Will I be operated on in the same hospital as my child?

This depends upon where your surgery takes place. Some hospitals look after both adults and children, whilst others are exclusively for children. Wherever you are, there will be a team of people caring for each of you.

The donor assessment and operation will always be performed in an adult transplant centre. This will be nearby if you and your child are cared for in separate hospitals.

If I am in a different hospital how long will I be separated from my child?

As a kidney donor you'll need time to recover from the immediate effects of the surgery. This is dependent upon the type of operation you have and your individual recovery. You will be anxious to see your child, but it's also important that you rest as much as possible in the first few days to help your recovery. You'll be able to stay in touch by telephone, and family members and friends will be able to visit both of you. If you're in separate hospitals, you'll be able to see your child once you have been discharged home.

If I am the parent and the donor, who will care for my child whilst I am in hospital?

You'll need to plan for the care of your child whilst you're in hospital well in advance, and your transplant team can help you to do this. In some families the non-donating parent stays with the child but a grandparent, aunt, uncle, or close family friend may be nominated instead. Whoever it is, it needs to be someone both you and your child feel comfortable with, and who understands what's involved in being with your child in hospital. You can speak to your child's doctor or nurse about this and they will be able to give you more information to help you decide. It's important to make childcare arrangements for any other children you may have and for some help at home immediately after you leave hospital. There are people who may be able to help you with this and any other practical concerns you may have.

If we are in the same hospital will I be able to see my child?

The staff caring for both you and your child realise how important it is that contact is maintained, and as soon as you are able they will bring you to visit.

If I am donating, how long will it take me to recover?

Recovery can take between four to twelve weeks, depending upon the donor operation and your individual progress. You'll need to rest following discharge from hospital, and will need to plan in advance for others to help care for your child and with day-to-day domestic tasks.



“ 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

Surgery and recovery

How is the kidney removed?

You'll be given a general anaesthetic which means that you'll be asleep during the operation. Usually the kidney is removed using keyhole surgery. You may have 2-4 keyhole wounds (around 1cm) and a slightly longer scar where the kidney was removed. Different surgeons use slightly different techniques, so please check with your own team where your scars are likely to be positioned if this is of concern to you.

Some type of keyhole surgery or similar technique is offered in all transplant centres around the UK. However, if there are any complications during the procedure, a larger wound in the side of the abdomen (tummy), known as 'open surgery' may be necessary. This happens in one or two out of every hundred operations of this type. Open surgery increases the time it will take for you to recover and will leave you with a larger scar.

How long will the operation take?

The operation usually takes approximately two to three hours. When you wake up you may have a tube draining your urine (a urinary catheter) and a drip (a tube inserted into your arm through which the medical team can keep you well hydrated and give you painkillers as needed). All of these will be removed over the following days as you recover.

How long will I be in hospital?

This varies depending on your individual recovery and type of surgery but the average stay is three to five days.

How painful will it be?

When you wake up you'll already have been given strong painkillers to help reduce any discomfort after the operation, and you'll continue to receive pain relief for as long as you need it in hospital. You'll also be given painkillers to take with you when you go home.

Will I need to take any medication after donating?

Apart from the painkillers mentioned above, you may also need to take antibiotics for a short period of time. However, you'll not need any long-term medication as a result of kidney donation.

What about follow-up checks?

You will be invited back to the hospital between two and six weeks after donation so that the team caring for you can check you are recovering and healing well. You will also be encouraged to attend a follow-up appointment every year after your donation. This is to ensure your remaining kidney is still functioning well and that you are fit and healthy after your donation. This also gives you an opportunity to raise any concerns you may have. If you don't live in the UK, you'll be advised how to arrange a follow-up appointment in your own country before you return home.

Practical considerations

Will I be covered by my health insurance?

You should check with your insurance company prior to donating. The transplant team is always happy to offer help and advice if your insurance company has any specific questions related to the donation and life-long risk for you.

What if I live in a different part of the UK from the person I am donating to?

You can still donate. Your transplant team can arrange for your donor assessment to take place at a hospital near to you if that is easier for you. Usually the donation will take place in the hospital where the person you are donating to is cared for. However, it may be possible to donate in a transplant centre closer to home, depending upon individual circumstances. Your kidney can always be transported safely to the recipient's transplant centre.

What if I live outside of the UK?

You can still donate to a friend or family member but there are some restrictions on donating to people with whom you have not had a close or previous relationship if you are not resident in the UK. Some preliminary tests can be arranged in your own country to see if you could be a suitable donor.

You should contact the Living Donor Co-ordinator in your recipient's transplant centre for further information and advice. If your first language is not English and you are considered to be a suitable donor, translation support is available for you throughout the detailed assessment process.



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

How long does the donor assessment process take?

The assessment process usually takes at least three months. However, it may take more or less time depending upon where you live, the hospital you're being assessed by and the types of tests you may require. Wherever possible, the assessment process is tailored around your other commitments.

How much time will I need to take off work?

Most transplant centres will try to arrange the tests and investigations before the operation around your work to minimise disruption to your job. It's sometimes possible to arrange for some of the tests to be done locally if you live a long way from the transplant centre. The recovery period after the operation usually lasts between four to eight weeks depending on the surgery, your individual recovery and the type of work you do (e.g. those with a desk-based job may be ready to return to work sooner than those with a very physical job). You should discuss this with your co-ordinator to get a better estimate of how much time you may need to take off work.

How will I be able to afford time off work?

There is a scheme in Scotland which enables donors to reclaim necessary expenses such as loss of earnings and travel. However, you should first discuss this with your employer and find out what is available under your (their) terms of employment around Statutory Sick Pay. Please talk to your Living Donor Co-ordinator about expenses at an early stage of the process if you may need to apply to the scheme, as there is some information that you'll need to read and an application form to complete. A letter from your employer and evidence of your expenses will also be necessary.



Deciding whether donating is right for you

Do some donors have trouble making the decision?

Donating a kidney is a very personal decision and is not something everyone feels comfortable with. Only you can decide if it's something you would like to volunteer to do. There are many different reasons why people give a kidney. Some people make the decision easily and others go through some soul searching before deciding. Being afraid of donating a kidney or feeling guilty about not wanting to donate is quite normal. The only 'right' decision is the one that makes you, the potential donor, feel comfortable. Finding out more information about living donation and talking things over with the medical team and your family and friends may help you make this decision.

Can I speak to somebody who has donated?

Sometimes it's useful to talk to someone who has already been through the process to help you make your decision. The co-ordinator at your local transplant centre can arrange this for you.

What if I decide against being a donor?

Volunteering to become a donor is entirely your choice and the journey between volunteering to donate and actually donating can be a difficult and emotional one. Sometimes people decide that donating isn't for them partway through the assessment process. It's important that you remember that you're free to change your mind at any point along the way. The transplant team wants you to be comfortable with the choice you make and will be supportive and respectful of any decision you make along the journey – even if that means not donating. Please talk to your co-ordinator at any point in the process if you're not certain that you wish to proceed with the donation.

Who makes the final decision?

Once all the tests have been completed they are assessed by the transplant team. The transplant will only take place if both the donor and recipient are willing to proceed and the transplant team is confident that both donor and recipient are healthy enough to go ahead safely.

Will the transplant be successful?

Living kidney transplantation is usually very successful with 96% of donated kidneys working well a year after the operation. This compares with a success rate of 93% for kidneys from deceased donors. However, there is no guarantee that the transplant will be successful and, sadly, a tiny number of people have very serious complications and the kidney has to be removed. It is important, before going ahead, to consider how you might feel if the transplant is not successful.

Next steps

What is the first thing I should do if I am thinking about being a donor?

If you know the person who you are considering donating to, please contact the hospital/transplant centre where they are cared for. They will give you some further information and begin the process for you if you wish to proceed.

If you do not have a recipient in mind and wish to donate anonymously, please contact the Living Donor Co-ordinator in your local transplant centre who can advise you on the process.

How is living organ donation governed in the UK?

In Scotland, the Human Tissue (Scotland) Act 2006 provide the legal framework for organ and tissue donation. The Human Tissue Authority (HTA) regulates the donation by living people of solid organs and part organs. The HTA give approval before any living donation can proceed. All donors will be assessed by an Independent Assessor, who is trained and accredited by the HTA as a routine part of the evaluation process to ensure that all the legal requirements have been met. The law requires that the donor must fully understand the nature and risks of the procedure and that there is no coercion, pressure or payment involved in the donation of the organ or part organ, which is illegal in the UK.

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

For more information on living kidney donation you should contact the living donor co-ordinator or transplant liaison nurse at your nearest Specialist Unit. You can do this by entering your postcode on the website: www.organdonationscotland.org/living-kidney-donation/contact-us

Charities

If you would like to talk to someone and to find out more you can contact any of the charities below:

British Kidney Patient Association – Improving life for kidney patients

Email: info@britishkidney-pa.co.uk

Tel: 01420 541424

Web: www.britishkidney-pa.co.uk

Give a Kidney – Charity raising awareness of non-directed altruistic donation and supporting donors and potential donors through the process

Email: giveakidney@gmail.com

Web: www.giveakidney.org

Kidney Research UK – Charity funding research and raising awareness of kidney disease

Email: enquiries@kidneyresearchuk.org

Helpline: 0845 070 7601

Web: www.kidneyresearchuk.org

Web based kidney health information service for kidney patients, their families and carers, as well as medical professionals and researchers.

Web: www.kidneyresearchuk.org/health-information

National Kidney Federation – Charity run by kidney patients for kidney patients

Email: helpline@kidney.org.uk

Helpline: 0845 601 02 09 Monday-Friday, 9am-5pm

Web: www.kidney.org.uk

Glossary of Terms

Deceased donor

A person who donates their organs and tissues 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: a regulatory body set up to implement the requirements of the Human Tissue Act.

Human Tissue Act

The Human Tissue Act 2004 for England, Wales and Northern Ireland and the Human Tissue (Scotland) Act 2006 provide the legal framework for organ and tissue donation in the UK. The rules set out by the Human Tissue Authority (HTA) specify certain requirements that must be met before donation from a living donor can take place. All living donor transplant operations must be approved by the HTA following independent assessment.

Independent Assessor

A trained and accredited person who is independent of the transplant team, who interviews donors and recipients of living organ transplantation in the UK and submits a report to the HTA.

Living Donor Transplant Co-ordinator

A specialist nurse who will be your 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.

National transplant list

A UK-wide list of patients waiting for a kidney transplant.

Non-directed altruistic donor

A person who donates one of their healthy kidneys for transplantation whilst alive, but to someone they do not know.

Paired/Pooled Donation

A scheme that enables kidneys from living donors throughout the UK to be 'swapped' for the benefit of patients waiting for a transplant.

Recipient

A person with kidney disease who receives a kidney transplant.

With acknowledgement to NHS Blood and Transplant. Originally compiled by a sub-group of the Living Donor Kidney Transplantation 2020 Strategy Implementation Group.

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

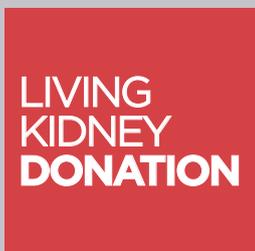
Visit: livingdonationscotland.org

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 6199



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Exceptional
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