

Could I be a living kidney donor?



www.organdonation.nhs.uk
enquiries@nhsbt.nhs.uk
0300 123 23 23



"Since donating my kidney a number of people have approached me and told me what an amazing person I am. I don't feel it, I just feel like a normal person who helped someone a little less fortunate than myself."

Carrie, donated a kidney to stranger in 2014

Could I be a living kidney donor?

A living kidney donor is a person who gives one of their healthy kidneys to someone with kidney failure who needs a transplant (the recipient). This could be a friend or family member, or someone they do not already know.

In the UK living kidney transplants have been performed since 1960 and currently around 1,100 such operations are performed each year, with a very high success rate.

A kidney transplant is transformational for someone with kidney disease, whether or not they are already having dialysis treatment. Volunteering to offer a kidney is a wonderful thing to do, but it is also an important decision and there are lots of things for you to consider. We hope this information will answer some of the questions that you may have.

You will find a glossary on page 15 that will explain some of the more technical terms or abbreviations that are used if these have not been explained in the text itself. These are underlined to help you.

Why do we need more living kidney donors?

- There are currently more than 5000 people in UK with kidney disease who are on the National Transplant List in need of a kidney – and the numbers are growing
- Hundreds of people in the UK die each year in need of a kidney transplant
- Unfortunately there are not enough kidneys donated from people who have died for everyone who needs a transplant
- The average waiting time for a kidney transplant from someone who has died is approximately three years. For some ethnic groups and people with rare tissue types the wait can often be five years, or much longer

Why is living kidney donation important?

- A successful transplant from a living donor is the best treatment option available for most people with kidney disease
- A kidney from a living donor (rather than one from someone who has died) offers the recipient the best opportunity of success as living donor kidneys usually last longer than those from deceased donors
- Generally people who receive a kidney from a living donor live for longer than those who receive one from a deceased donor and much longer than they would be expected to live if they did not receive a kidney transplant
- Living kidney donation allows the operation to be planned at a time that is convenient for the recipient, donor and clinical team

- With a transplant, some people can avoid needing dialysis treatment entirely. This is even better than having a transplant once dialysis has started because recipients who receive a kidney before they have to go onto dialysis generally live longer than those who do not.

Donating a kidney

Could I volunteer to be a living kidney donor?

Healthy people who wish to help a loved one or a stranger with kidney disease may volunteer to give a kidney. Volunteer is the key word – this must be something that you choose to do and feel comfortable doing.

Anyone volunteering will be asked to undertake a series of tests so that the medical team can be absolutely sure that you are suitable to donate. Your health and safety is of primary concern and it is important to be aware from the start that, even if you want to be a donor, not everyone is suitable and you may be unable to donate.

It is also important to remember that even if you do volunteer, you can change your mind at any point in the process – right up to the time of surgery.

Who can donate?

Most often donors are a close relative of the recipient, such as a family member, partner or good friend. However, people who do not know anyone with kidney disease, but who wish to donate, can also provide a kidney for someone on the national transplant list. These people are known as non-directed altruistic donors. To find out more information on non-directed altruistic donation please visit www.odt.nhs.uk/donation/living-donation.

Sometimes a donor and a recipient pair (who already know each other) may not 'match' with each other because of blood group or HLA (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 is called pooled donation. Non-directed altruistic donors are also 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.

Is there an age limit for donors?

In England, Wales and Northern Ireland, there is no lower age limit specified in law for a person to be considered as a living kidney donor. In Scotland, only people over 16 years of age can be legally considered. However, almost all donors are over 18 years old and children are only considered in very

exceptional circumstances, with court approval. Children are not considered as non-directed donors.

There is no maximum age limit for donation. Donors are 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 more than 80 years of age.

How will I know if I am suitable to donate?

You will undergo a number of medical and surgical tests to check that you are fit and healthy enough to donate. A kidney will never be removed from someone unless the doctors are satisfied that the risks to them, in the short and long-term, are acceptably low.

Some people who wish to donate find that they are not able to do so because of the results of 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 Coordinator, who will guide you through the entire process. S/he will talk you through all of the tests that you need to undertake. These are to make sure you are healthy enough to donate and that your kidneys are working properly. The tests are generally not painful or invasive (but you will be asked for lots of blood samples along the way). They 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 is possible that the tests may show a condition or illness that you did not 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. This is because 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 will be asked about your reasons for donating and your understanding of the process. The Independent Assessor checks that you are not being pressurised into donating, or being paid to do so, which would be against the law, and asks you to sign a declaration. The Human Tissue Authority needs to approve your donation in order for it to go ahead but, in general, it is very straightforward and you should not be anxious about it.

The risks

This information does not cover detailed medical questions; it is designed to give you general information about donating a kidney based on the advice of medical professionals and currently accepted guidance in the UK, from the research that is available to them. Your healthcare team will discuss risk with you in more detail and on an individual basis, particularly if there are certain concerns about you or your recipient because of your lifestyle, medical history or demographic. Risk must be considered on an individual basis based upon your individual circumstances.

It is also important to note that research in this area is continually evolving and does not cover every eventuality. Not every possible consequence of donation has been fully researched.

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 is a similar risk to that of having an appendix removed.

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 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. As with any surgery there can be less common and unexpected complications.

There is also the risk of damage to your emotional well-being or mental health if things do not work out as expected, for example, if there are complications for you or the recipient and particularly if the transplant does not work and has to be taken out.

For non-directed altruistic donors and donors in the paired/ pooled donation scheme, it is likely that you will 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 are not disappointed if you do not hear anything from your recipient.

It is very important for you to consider all these risks when you are 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 is important to be aware that every donation carries risks and it is not possible to cover every eventuality when considering risk. However, some of the most notable post-donation research indicates the following:

- Some studies have indicated that there is a slightly higher chance of a small increase in your blood pressure or the amount of protein in your urine as a result of having one kidney. However, these are checked at annual follow-up and, if found, can be treated.
- The overall risk of developing significant kidney disease in your remaining kidney after donation is very low, occurring in less than one in 200 (0.5%) donors, and it is much less in kidney donors than it is in the general (unscreened) population (because kidney donors are, of course, pre-screened to ensure they are healthy).
- Compared to the general public, most kidney donors have equivalent (or better) survival, excellent quality of life, and no increase in end-stage kidney disease (ESKD – kidney disease).
- Some studies have indicated a slightly increased incidence of ESKD post-donation among certain groups, in particular, black donors, younger donors, donors genetically related to their recipients, donors related to recipients with immunological causes of their kidney failure, and overweight donors. However, the risk is still lower than that of the general (unscreened) population.
- Whilst most women have uncomplicated pregnancies after donation, there is a slightly increased risk of gestational hypertension or pre-eclampsia.
- It is also important to be aware that, although risks across the board are generally very low, every individual is different and it is possible for other uncommon complications to occur. For example, although rare, on-going fatigue and persistent pain have been reported by small numbers of the thousands of living donors. However, most donors lead a normal, healthy life after they have donated and are able to do all the activities that they were doing before.

When considering donation, it is important for donors to think about how they might feel if something unlikely or unusual were to happen to them and to discuss these concerns with their clinical team as part of the assessment process.

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 coordinator 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.

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 are 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 is 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 twelve 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 coordinator 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 UK scheme 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 Coordinator 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 will need to read and an application form to complete. A letter from your employer and evidence of your expenses will also be necessary.

Cultural considerations

What are the cultural views on living donation?

The UK is increasingly multicultural. If you have any concerns about living donation contact your Community Association Group or community leaders.

What are the religious views on living donation?

Most religions support living donation as they view it as a gift to a loved one. However, if you have any doubt, you should contact your religious leader or place of worship for support and advice.

Surgery and recovery

How is the kidney removed?

You will be given a general anaesthetic which means that you will be asleep during the operation. Usually the kidney is removed using keyhole surgery. You will have 2-4 keyhole wounds (around 1cm) and, depending on the technique used, 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 pain killers as needed). You may also have a tube draining fluid from the main surgery area. 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 will already have been given strong painkillers to help reduce any discomfort after the operation and you will continue to receive pain relief for as long as you need it in hospital. You will 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 will not need any long-term medication as a result of kidney donation.

What about follow-up?

We will ask you back to the hospital between two and six weeks after donation so we can check that you are recovering and healing well. We also encourage you to attend a follow-up appointment every year after your donation so we can make sure your remaining kidney is still functioning well and that you are still fit and healthy after your donation. This also gives you an opportunity to raise any concerns you may have. If you do not live in the UK, you will be advised how to arrange follow-up in your own country before you return home.

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 is useful to talk to someone who has already been through the process to help you make your decision. The coordinator 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 is not for them part-way through the assessment process. It is important that you remember that you are 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 coordinator at any point in the process if you are 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 coordinator in your local transplant centre who can advise you on the process. There is a full list of transplant centres at www.odt.nhs.uk/transplantation/transplant-units-in-uk/

How is living organ donation governed in the UK?

In England, Wales and Northern Ireland the [Human Tissue Act 2004](#), and in Scotland the [Human Tissue \(Scotland\) Act 2006](#), provide the legal framework for organ and tissue donation in the UK. 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.

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 will 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 is also important that you rest as much as possible in the first few days to help your recovery. You will be able to stay in touch by telephone and family members and friends will be able to visit both of you. If you are in separate hospitals, you will 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 will need to plan for the care of your child whilst you are 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 is 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 is 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 will need to rest following discharge from hospital and will need to plan in advance for others to help caring for your child and with day-to-day domestic tasks.

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 coordinator or transplant liaison nurse at your nearest Renal Unit, visit www.odt.nhs.uk/transplantation/transplant-units-in-uk or call 0300 123 23 23.

NHS Blood and Transplant

Email enquiries@nhsbt.nhs.uk

Tel: 0300 123 23 23

Web www.organdonation.nhs.uk

Human Tissue Authority

151 Buckingham Palace Road, London, SW1W 9SZ

Email enquiries@hta.gov.uk

Tel 020 7269 1900

Web www.hta.gov.uk

Living Donation, Scotland:

www.organdonationscotland.org/tell-me-about-living-donation

Living Donation, Northern Ireland:

www.donatelife.co.uk

Charities

Kidney Care UK – Improving life for kidney patients

Email info@kidneycareuk.org

Tel: 01420 541424

Web www.britishkidney-pa.co.uk

Gift of Living Donation – exists to promote living kidney donation and raise awareness of organ donation in the African and Caribbean community.

Email info@giftoflivingdonation.co.uk

Web www.giftoflivingdonation.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 (2004).

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 Coordinator

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.

NHSBT

NHS Blood and Transplant – a special health authority of the NHS which is responsible for overseeing the supply of blood, organs and tissues. Within NHSBT the Organ Donation and Transplantation (ODT) Directorate is responsible for ensuring that donated organs and tissues are matched to patients who need a transplant and are used in the fairest way.

Non-directed altruistic donor

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

Sources

UK Living Donor Kidney Transplantation, BTS & Renal Association, 3rd Edition, May 2011.

Living Kidney donation: Your Questions Answered, Gift of Life, 2015.

Guidance for Living Organ Donors on the Human Tissue Authority's Independent Assessment Process, revised June 2015.

Organ donation and religious perspectives, NHSBT, 2009.

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