NHS
Blood and Transplant

Can I donate a kidney **to someone I don’t know?**

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

Altruistic (non-directed) kidney donation

There are currently thousands of people in the UK in need of a kidney transplant. Most of us can live perfectly well with only one kidney, and yet nearly all of us have two. Over the past 60 years many people across the world have given one of their healthy kidneys to help someone with kidney disease.

In recent years, a growing number of people have offered one of their kidneys anonymously to someone on the National Transplant list. A living person who donates one of their kidneys to someone they do not already know is called a non-directed altruistic kidney donor. Hundreds of people have now donated a kidney in this way, alongside the thousands who have donated to a family member or friend.

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 may also find it useful to read ‘could I be a living kidney donor?’ for further information.

> *“It’s not often you get the opportunity to make such a significant difference to someone’s life. If I had another ‘spare’, I wouldn’t hesitate to do it again.”*
>
> A non-directed kidney donor

> *“I got my life back.”*
>
> A recipient of a kidney transplant

Frequently asked questions

Why do we need more living kidney donors?

- There are more than 5,000 people with kidney disease in the UK in need of a transplant
- Hundreds of people in the UK die each year waiting for a kidney transplant
- 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 and work better 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 and the donor. 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 dialysis generally live longer than those who do not.

Could I volunteer to be a non-directed altruistic living kidney donor?

Healthy people who wish to help someone 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.

Any adult can volunteer to be considered as a non-directed altruistic donor (over 18 years of age in England, Northern Ireland and Wales, over 16 years of age in Scotland).

You will be asked to undertake a series of tests so that the medical team can be absolutely sure that you are healthy enough 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.

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 coordinators, 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.

You will be required 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.

All donors 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.

What happens to my donated kidney?

Our aim is to ensure your donation benefits as many people on the waiting list as possible. All non-directed donors are entered into the UK Living Kidney Sharing Schemes to initiate a chain of up to three transplants, unless there is a recipient with high priority for transplant on the national transplant list. This is known as an altruistic donor chain and your kidney donation may make it possible for up to three people to receive a transplant, who would otherwise not have had the chance. If you cannot be matched to a recipient to initiate a chain, the kidney is donated to the most suitable recipient on the national transplant list, using the same national allocation scheme that is used for deceased donor kidneys.

Your living donor coordinator will explain how this works in more detail but you can also read the leaflet 'UK living kidney sharing schemes' or visit www.organdonation.nhs.uk to find out more.

Can I select who I donate to e.g. a child, someone in my home town etc.?

Non-directed donors cannot specify the type of person whom they wish to receive their kidney. The kidneys are allocated to both children and adults using national allocation schemes which have been carefully designed to ensure that they are fair to everyone and that each kidney is put to the best possible use so that as many patients as possible within the UK benefit from a successful transplant.

Can I donate to a specific patient who I heard about on Facebook, on TV or in the newspaper?

Donating a kidney to someone specific with whom you have no previous existing relationship is called Directed Altruistic Donation. The likelihood of being compatible with someone whom you identify in this way is rare but may be possible. You should contact the potential recipient's transplant centre for advice and further information but if you do not know where the recipient is being cared for, the living donor team in your closest transplant centre will be able to advise you. A list of all the transplant centres can be found on the organ donation website.

What do I need to know if I am going to volunteer as a directed altruistic donor?

When people post stories on Facebook or appeal for a donor through the media, it is usually because the recipient has waited a long time for a kidney or that a loved one simply wants to do something to help them. There are many reasons why some people wait longer than others for a transplant but mostly it is because it is difficult to find a compatible kidney from either a living or deceased donor.

Although media and social media reach many people, the likelihood of you being a suitable donor for the patient appealing for a kidney is very small, particularly if the recipient has a rare HLA type (tissue type) and has waited a long time to find a donor. One appeal can generate interest from lots of people and not everyone can be assessed immediately or all at the same time.

You need to be realistic about what this means for you. Here are some things to think about before you volunteer:

- **The likelihood of you being a suitable donor is very small** – particularly if a patient has waited a long time for a kidney.
- **Please be patient** – you may be one of many donors who respond to an appeal for a specific person within a short space of time and the transplant centre needs to organise initial screening-blood tests and appointments as sensibly as possible for everyone who volunteers. These cannot all be done at the same time and you may need to wait.
- **Are you happy for your recipient to know who you are?** In directed altruistic donation, it is usual to meet the person to whom you plan to donate – the law may make exceptions in specific circumstances but, generally, it is expected that donor and recipient will not be anonymous to one another.

- **Know before you go** – before you offer to be tested, understand what might be involved for you by reading this information and researching other resources about living kidney donation. Giving a kidney is a wonderful gift but it is a big decision and needs careful consideration. Your recipient will be pinning a lot of hope on every person who volunteers so it is a good idea to give it some thought before you step forward.
- **Would you be willing to think about non-directed donation (to someone else on the National Transplant List) if you could not donate to the person whom you identified?** If you are not a suitable donor for the patient, or they successfully find a different donor – would you still be willing to donate to someone else in need? You might be able to help more people by making a chain of transplants possible from your single donation as a non-directed donor.

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).
- 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

What if I live outside of the UK?

There are some restrictions on donating as a non-directed or directed altruistic donor if you are not resident in the UK. If the recipient you wish to donate to is known to you, you should contact the Living Donor coordinator in their transplant unit (see organ donation website) or, if not, please contact NHSBT on enquiries@nhsbt.nhs.uk for further 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.

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.

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. If you require additional tests due to abnormal results then this will lengthen the assessment process. 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 the living donor team 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 should 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 if donation is right for you

Can I speak to somebody who has donated anonymously?

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 you 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.

Celia: "It seemed to me that as a fit and healthy person, I could give my spare kidney to someone who could then have a more normal life, away from the tyranny of dialysis. It didn't matter to me that the recipient was unknown. It was a very satisfying experience and I'm thrilled to have been able to donate."

Celia donated a kidney to someone in need in 2015.

Next steps

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

You can choose to contact any transplant centre but, bearing in mind you will need several appointments and you may wish to be near your family when you donate, it is advisable to contact the living donor coordinators in your local transplant centre first for further advice and information. If you are considering directed donation to a specific patient, it is usually better to contact your transplant centre first so that the team there can coordinate everything for you.

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.

More information

Whilst non-directed altruistic donation differs from donation between families and friends because the donor and recipient are not known to each other, the process of being assessed and the donor operation is almost the same. Here are some sources of information that you might find particularly useful.

The NHS Blood and Transplant (NHSBT) website at www.organdonation.nhs.uk has lots of up-to-date information about becoming a living donor, including answers to frequently asked questions and latest statistics. NHSBT also has an enquiry line, **0300 123 23 23** which you can call or email if you cannot find what you are looking for or need more detailed or expert advice.

It may be helpful to speak to someone who has been through the donation process.

There are numerous patient associations that can help you and the web-links to some of these are included on the NHSBT website and in the information leaflets. In particular, Give a Kidney at www.giveakidney.org (email giveakidney@gmail.com) is a Charity that aims to increase awareness about altruistic donation and to provide support for donors who are considering donating a kidney to someone they do not already know.

The Human Tissue Authority at www.hta.gov.uk provides helpful information for potential donors about what is required under UK law for all aspects of living kidney donation, including non-directed altruistic donation.

You can also read the latest *'UK Guidelines for Living Donor Kidney Transplantation'*, on The British Transplantation Society website at www.bts.org.uk in the *'Standards and Guidelines'* section. These are professional guidelines which provide detailed recommendations for the assessment and preparation of living donors.

Prefer to talk to someone about it?

If you do not have access to the internet or would prefer simply to talk to someone you can contact a Living Donor coordinator in your closest kidney transplant centre.

It may feel like a big step to 'cold call' someone, but every kidney transplant centre in the UK has a team like this who are happy to speak to you about living kidney donation and to answer any questions you may have, whether you are just starting to think about it or have already started the process.

Your conversation is completely confidential and does not tie you into anything at all. The coordinators will also be able to send you more information to look at home.

If you have already done your research and wish to start the process of being assessed as a donor, they will be able to talk you through the first steps. They can also put you in contact with previous donors if you would like to speak to someone about their experience of donating.

You can contact any transplant centre, but it is a good idea to start with the one that is closest to where you live, as it is likely to be more convenient for you to attend appointments locally.

If you are not sure which transplant centre covers your area of the country or are unsure who to contact, you can email your enquiry to NHS Blood and Transplant at enquiries@nhsbt.nhs.uk and they will be able to guide you.

Compiled by a sub-group of the Living Donor Kidney Transplantation 2020 Strategy Implementation Group.

Glossary of Terms

Antibodies

Antibodies are produced by the body when it detects something ‘foreign’. Their purpose is to remove such substances which can be harmful (e.g. a virus or bacteria), from the body. In general this is a good thing, but it can be a problem in transplantation when an entire ‘foreign’ kidney is given to someone. If a recipient has antibodies against the donor’s blood group or HLA type, that donor’s kidney is unsuitable for the recipient as the antibodies will attack the ‘foreign’ kidney and cause rejection. Blood group antibodies are in the blood from early in life and HLA type antibodies are made if the recipient has previously been in contact with another person’s cells through pregnancy (the baby is half of the father), blood transfusion or a previous organ transplant.

Compatible

When the person needing a kidney transplant does not have antibodies to the blood group or tissue (HLA) type of the donor and a straightforward transplant between them is possible.

Deceased donor

A person who donates their organs and tissues for transplantation after their death.

Donor-recipient pair

A person who needs a transplant and their willing donor who are registered together into the paired/pooled scheme.

Exchange

Matched donor recipient pairs between whom kidneys are swapped.

HLA type

This refers to proteins known as Human Lymphocyte Antigens (HLA) that 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. 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 (IA)

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

Incompatible

When someone suitable to donate a kidney cannot give to their loved one who needs a transplant in a direct, straightforward way because they do not match – either they are the wrong blood group or the wrong tissue type.

Living donor kidney transplantation

Kidney transplantation between someone who donates a kidney during their lifetime (living donor) to a recipient who needs a kidney transplant.

Matching run

Kidney matching run carried out by NHSBT, via a computer program four times a year, to identify all paired/pooled exchanges and altruistic donor chains.

UK Living Kidney Sharing Scheme

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

National transplant list

A UK-wide list of patients awaiting a kidney.

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.

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

NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

For more information
Visit nhsbt.nhs.uk
Email enquiries@nhsbt.nhs.uk
Call 0300 123 23 23

1819033 OLC287 web