

What to consider if you are thinking about being a live kidney donor

Renal and Transplant Department

Information for Patients

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Live kidney donation

A kidney transplant is the best treatment for the majority of patients with kidney failure. The number of people waiting for a kidney transplant is steadily increasing. There are not enough kidneys available to meet this current growing need. This means many people normally have to wait several years before they can have a kidney transplant.

The kidney used in a transplant operation can be from people donating organs after they have died (deceased donor transplantation), or they can be from living donors (living donor transplantation). Just under half of the transplants done in the UK are now done using kidneys given by living donors.

Most people are born with 2 kidneys, but it is possible to lead a perfectly normal life with only 1 kidney. If a kidney is removed, the remaining kidney increases its work capacity and can perform at an adequate capacity to maintain normal kidney function.

There are potential risks of donating a kidney which are explained in this leaflet. This may help those who are considering donation to decide if this is the right thing for them to do.

Who can donate a kidney?

The donor may be a blood relative of the recipient, but this is not essential. A donor who is not related can be known to the recipient and usually has a personal relationship with them, such as partner, friend or work colleague.

It is also now possible for donors to donate a kidney to someone they do not know, who is on the national waiting list. This is known as altruistic donation.

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How is my suitability of being a kidney donor assessed?

There are many factors to consider before deciding whether someone is suitable to donate their kidney. These include an assessment of your age, health and social circumstances. An assessment is also done to determine if you have potential risks that could lead to problems should you donate a kidney.

Living organ donation is allowed under the Human Tissue Act 2004, but there are both legal and medical constraints:

Legal constraints:

The donor must be over 18 years old. You must genuinely want to donate your kidney and not be under any emotional pressure to do so. Forceful pressure (coercion) by any parties, or receiving any form of payment is illegal in this country.

All potential living donors have to meet with a representative of the Human Tissue Authority (HTA) and have their offer of donation approved before the operation can take place.

Medical constraints:

Potential donors have to undergo many tests to make sure they are medically fit to donate a kidney. This means that they tend to be under the age of 80. You must have 2 healthy kidneys and have excellent kidney function. This is to make sure that you will be able to lead a normal life with just 1 kidney after donation.

You should not have any disease that may affect the function of the remaining kidney in later life. This includes potential of developing conditions such as diabetes and uncontrolled high blood pressure. You must not have a history of kidney disease (there are exceptions such as kidney stones), or some types of cancer. You must also be able to understand and remember information.

Potential donors must not be carriers of any virus that might be passed onto the recipient. This includes hepatitis B, E or C, HTLV 1 & 2 or the HIV virus. Blood tests for these viruses are a routine part of the assessment for all potential donors, both living and deceased.

Historically the donor and the recipient needed to have compatible blood groups, but it is now possible to transplant between people who have different blood groups. Please ask if you would like more information about this.

If you and the recipient have compatible tissue types and blood groups the process can continue and is known as a directed match. If the tissue types are not compatible to the intended recipient, the national paired pool scheme can be considered. Further information on this can be discussed with the Live Donor Co-ordinator. Family donors and recipients should be aware that testing of tissue types could reveal misattributed genetic identity (1 in 200 cases). Both parties will need to decide at the start of the process that if such information was identified, whether they would want us to reveal this information to them or not.

Up to 70% of people who offer to donate a kidney will be found to be not suitable. Some of these will have a medical problem which makes them unsuitable. Many will not have a good enough kidney function to allow them to live normally with just 1 kidney after donation.

What happens if I change my mind?

As a potential donor you have the right to change your mind at any time before the operation. If you give reasons for changing your mind, it will be kept confidential. You should not feel any pressure from anyone to change your decision. You are encouraged to express any doubts and concerns at any time. The operation will be delayed until you decide whether you are happy to proceed or not.

What tests will I need to have to check if I am suitable?

All potential donors will need to have a series of medical tests to see if they are suitable to donate a kidney. These are to make sure you are in good health, are physically and mentally fit for the operation, and to assess whether there is a risk of you experiencing any long-term problems as a result of donating a kidney.

The tests will be arranged by the Transplant Co-ordinators. They will try to arrange them to fit in with your family and work commitments.

The tests include a routine medical examination, blood and urine tests, electrocardiograph (ECG) of the heart and a chest X-ray. If you are over 60 years of age you will also have an echocardiogram (ECHO) scan to look at your heart with an exercise test. This will show how well your heart is working.

Detailed tests of your kidney function will be needed. This will show up any abnormalities in the kidneys. A test called a glomerular filtration test (GFR) will show how well your kidneys are working. This involves an injection of a mildly radioactive substance into a vein in your arm. This is taken up and removed by the kidneys. A blood test is taken at 2 different time points after the injection. From this the filtration rate through the kidneys is calculated.

If these tests are all normal then a scan called a renal CT angiogram is arranged. This scan will give a detailed picture of the blood supply to each kidney. It will help the surgeon decide which would be the best kidney to remove. The scan is done in an outpatient clinic and usually takes around 30 minutes. It involves the injection of a contrast dye into a vein in your arm. After this the CT scan pictures are taken. The scan can sometimes reveal issues which may need further tests and possible treatment (e.g. stones, lumps), and if certain conditions are found it may prevent you from being a donor.

If you are approved as being a suitable donor after having all required assessments, a date for the operation will be arranged. The operation is called a **live donor nephrectomy** (nephro means kidney and ectomy means removal). It is done by hand assisted keyhole surgery under a general anaesthetic and takes around 2 to 3 hours. A small wound will be made in the lower abdomen to remove the kidney which is about the size of your clenched fist. This is similar to the wound for a caesarean section for childbirth.

What are the risks to the donor?

Living kidney donation has been practised worldwide for over 50 years. The life expectancy of a donor is not affected by having donated a kidney. All operations carry risks. It is essential that anyone considering live kidney donation should know what these are.

The physical risks of having a kidney removed can be divided into immediate risks and long-term risks. Immediate risks apply at the time of the operation and during the recovery period. Long-term risks might arise years later.

The psychological effects of kidney donation also need to be considered.

Immediate risks:

- As with any operation, there is a risk of dying during the procedure or in the immediate period after surgery. The risk of dying as a result of live donor nephrectomy is about **1 in 3000**.
- Significant but non-fatal complications affect around 1 in 10 to 1 in 50. These include bleeding and infections which need antibiotics. Such complications may increase your hospital stay by a few days, but generally leave no long-term after effects. More details will be given to you about the risks of the surgery when you see the consultant.
- During the operation the surgeon may need to change from the hand assisted laparoscopic keyhole method to an open surgery method, to complete the operation. The risk of this happening is less than 1 in 100.
- Possibility of damage to surrounding structures (liver, spleen, bowel, blood vessels, nerves, adrenal gland, gonadal blood supply leading to testicular atrophy (males)).
- Possibility of complications from the surgical wound (fluid collections (lymph), infections, wound break down, wound pain, scar and hernia).

Long-term risks:

- In the long term there may be an increase in the amount of protein in the urine of kidney donors. If this is identified and there is also a decline in your kidney function, then you may need specific advice from a kidney doctor.
- As a kidney donor, you are more likely to need to take tablets to control your blood pressure in the future.
- There is a very small chance of developing a hernia at the site of the surgical wound. If this causes problems it may need to be repaired at some point in the future.
- The overall risk of your remaining kidney no longer being able to work to meet your body's needs (developing end stage renal disease) remains very low, less than 1 in 200 (0.5%) donors, and this is much less than that of the general (unscreened) population.

Will it hurt?

There is likely to be some pain from your wound after surgery. Painkillers, such as morphine, are given into a vein in your arm immediately after the operation. This can be controlled by the patient and is called patient controlled analgesia (PCA).

Tablets for pain relief are also given and a supply of these will be given to you when you leave hospital. Any pain will normally fade to just a feeling of discomfort within a few days.

It is important that donors do not take non-steroidal anti-inflammatory drugs (NSAID) after surgery, and you will never be able to take these again for life. These type of painkillers can potentially damage your remaining kidney. They include ibuprofen (Nurofen), diclofenac (Voltarol) and naproxen (Naprosyn).

How long will it take to get back to normal after surgery?

You will be encouraged to sit out of bed the day after your operation and to walk around the ward. This helps to prevent the complications of immobility and will help you to recover more quickly. These include constipation, chest infection and developing blood clots in the legs.

Most donors can go home 2 to 3 days after their operation if they are well. It is normal to feel tired when you get home. This usually improves within the first few days at home.

You will not need to take any medication as a result of having donated a kidney. You should eat a healthy diet and drink plenty of fluids. It is important that you do not put on excessive weight as this can put a strain on your remaining kidney.

The time taken to return to normal activities varies from person to person. You are advised to avoid heavy lifting for 12 weeks after surgery. This includes lifting heavy shopping, pets and small children. Most donors will need around 4 weeks off work, depending on the nature of their work. You should not drive for about 2 to 3 weeks after your operation. Your doctor will advise you when it is safe for you to drive again, which will usually be at your first clinic appointment, 2 to 3 weeks after surgery.

Once you have recovered from surgery, you should have the same physical capacity as you had before donation. You will be able to resume normal sporting activities.

It is safe for female donors to become pregnant (although there is a slight increase in the risk of pre-eclampsia), but you are strongly advised to have a planned pregnancy and wait for 1 year after your surgery. Should you become pregnant, your GP should immediately refer you to a maternity doctor (obstetrician) for advice.

The fertility of male donors will not be affected.

How will I be able to afford time off work?

There is a UK scheme which allows donors to reclaim necessary expenses such as loss of earnings and travel. It is important however that you first discuss this with your employer and find out what is available under the terms of your employment around sickness benefits.

Please talk to the Living Donor Co-ordinator about any concerns you may have about your finances in the early stage of the process. If you need to apply to the scheme 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 needed.

Psychological effects of kidney donation

These are more difficult to measure than the physical effects. It is normal for donors to feel anxious before their surgery. Some donors report feeling emotional in the first few days after their operation. Some experience a feeling of anti-climax or feel a bit depressed when they go home. Others feel relieved and an increase in self-worth when they see the benefit of the transplant to the recipient.

Both recipient and donor need to consider the risk of the transplant being unsuccessful. This would obviously cause great disappointment to you both, as well as to other family members. Donors may experience feelings of guilt or even anger that their kidney has not worked. Recipients may experience guilt at having put the donor through an unnecessary operation.

All potential donors should understand that the long-term success of a transplant operation can **never** be guaranteed. You should consider whether you could cope with the possibility of the transplant failing.

What benefits are there for the recipient from having a transplant from a live donor?

One important advantage for recipients of a living donor transplant is the ability to plan the operation at a convenient time. It can be planned around work and family commitments, and holidays of the donor and recipient. It may be possible to time it to avoid the need to start dialysis (GFR 15 and below). This is known as pre-emptive transplantation.

A kidney from a living donor will usually be in a better condition than one from a deceased donor. This is because an approved donor will be fit and healthy and will have excellent kidney function.

The donor and recipient operations follow each other in the same operating theatre at Leicester General Hospital. This allows the time the kidney is without a blood supply to be kept to a minimum. If the living donor is in another transplant centre, the kidney will need to be stored in ice so it can then safely be transported to the recipient's transplant centre.

A successful kidney transplant from a living donor is likely to last longer than a kidney from a deceased donor.

How successful are transplants from live donors?

Around 98 to 99% of kidneys from living donors and 95% from deceased donors are functioning 1 year after transplantation. 92% of kidneys from living donors and 86% from deceased donors are functioning 5 years after transplantation (this is the NHS Blood and Transplant (NHSBT) published data for Leicester, which is in line with national averages).

After a transplant, the average time a kidney works without the need for dialysis, is longer if it came from a living donor than from a deceased donor, and this is around 15 to 20 years.

What if I want to donate a kidney but live abroad?

We support potential donors for our recipients, after the potential donor approaches our Live Donor Co-ordinator.

You must have all your initial screening assessments done in your country of residence at your own expense. This will include basic tests to confirm your blood group, tissue type, kidney function and virology screening. Any disease identified will need to be addressed in your country of residence. You will need to provide proof of these tests to the Live Donor Co-ordinator.

If the initial screening is satisfactory, a screening questionnaire will be sent out to you to assess your medical suitability. All information leaflets will also be provided along with the questionnaire. Once this information has been received and reviewed by our medical staff and our laboratories, if satisfactory, a letter of support for your visa application will be provided.

Any disease identified in the screening process when you are in the UK, not related to the donation surgery, will need to be addressed at your own cost in the UK or you will need to return to your country for treatment. This may prevent you from being a donor.

All treatment costs related to the live donor nephrectomy operation will be funded by the NHS once the donor is in the UK. Any long-term follow-up checks or treatment needed will be in the donor's country of residence and will not be funded by the NHS.

If you are approved to be a live kidney donor you will be contacted to start the process.

Summary

Only you can decide whether you wish to offer a kidney to another person.

For the recipient it means a significantly better chance of having a kidney that works well for many years.

It involves a significant major operation for the donor with potential risks. The risks to the donor must be balanced against their wish to help the recipient.

Contact details

If you are considering living kidney donation and would like to discuss it further please contact:

Renal Transplant Live Donor Co-ordinator

Leicester General Hospital

Tel: 0116 258 4117 (direct line)

Mobile: **07879 418287**

If you have any questions, write them down here to remind you what to ask:

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اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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