

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 growing. There are not enough kidneys available to meet this need. This means many people have to wait many 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).

Most people are born with 2 kidneys. It is possible to live a normal life with only 1 kidney. If a kidney is removed, the other kidney increases its work capacity. It can do the job of 2 kidney's and have normal kidney function.

This leaflet will explain the risks of donating a kidney.

Who can donate a kidney?

The donor may be a blood relative of the recipient. The donor can also be someone who is not a blood relative. The donor can be the recipients partner, friend or work colleague.

Donors can donate a kidney to someone they do not know. This would be a person who is on the national waiting list. This is called altruistic donation.

How do doctors check if I can give someone my kidney?

Doctors will look at many factors before deciding if someone is suitable to donate their kidney. These include an assessment of your age, health and social circumstances. They do an assessment to see if you have potential risks that could lead to problems if you donate a kidney.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

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. You must not be under any emotional pressure to donate. Forceful pressure (coercion) by any parties, or getting 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). They have to get their offer of donation approved before the operation can take place.

Medical constraints:

Potential donors have to do 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 developing conditions like 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.

Before the donor and the recipient needed to have compatible blood groups. 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. This is known as a directed match.

If the tissue types are not compatible to the recipient, the national paired pool scheme can be used. You can talk about this with the Live Donor Co-ordinator.

Family donors and recipients should know that testing of tissue types could reveal if family members are not blood related (1 in 200 cases). Both members 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 let 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. The reason you give for changing your mind 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 medical tests to see if they are suitable to donate a kidney. These are to make sure you are in good health, physically and mentally fit for the operation, and to see if there is a risk of you having any long-term problems from donating a kidney.

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

The tests include:

- a routine medical examination
- blood tests
- pee (urine) tests
- electrocardiograph (ECG) of the heart
- 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.

We will need to do detailed tests of your kidney function. This will show any abnormalities in the kidneys. A test called a glomerular filtration test (GFR) will show how well your kidneys are working. We will need to inject you with a mild radioactive substance into a vein in your arm. This is taken up and removed by the kidneys. We take blood test at different time points after giving you the injection. From this we work out the filtration rate of the kidneys.

If these tests are all normal then we will do a scan called a renal CT angiogram. 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. We will inject of a contrast dye into a vein in your arm. After this the CT scan takes pictures. The scan can sometimes show issues which may need more testing. It can also show if you need treatment (for stones or lumps) and if certain conditions are found it may stop you from being a donor.

All donors results from investigations are looked through at a multi-disciplinary team meeting (MDT). The MDT will help assess if someone is suitable or not.

If you are approved as being a suitable donor after all the assessments, we will arrange a date for the operation.

The operation is called a **live donor nephrectomy** (nephro means kidney and ectomy means removal). We do this by hand assisted keyhole surgery. You will be under general anaesthetic. It takes around 2 to 3 hours to do. We will make a small wound in the lower abdomen to remove the kidney. The kidney 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.

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

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 right after surgery. The risk of dying from a live donor nephrectomy is about **1 in 3000 cases**.
- 1 in 10 to 1 in 50 cases can have bleeding or get an infection. We will give you antibiotics for this. You will need to stay in hospital for a few days. You will have not long-term after effects. You can get more details 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 cases.
- There is a possibility of damage to surrounding structures like your:
 - liver
 - spleen
 - bowel
 - blood vessels
 - nerves
 - adrenal gland
 - gonadal blood supply leading to testicular atrophy (males)
- Possibility of complications from the surgical wound include:
 - fluid collections (lymph)
 - infections
 - wound break down
 - wound pain
 - scar
 - hernia

Long-term risks:

- There may be an increase in the amount of protein in urine of the kidney donor. If this is found and your kidney is not working well, you might need to see a special kidney doctor for help.
- 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 getting a hernia where the surgical wound is. If this causes problems we may need to repair this at some point in the future.
- The 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 cases (0.5%) donors. This is much less than that of the general (unscreened) population.

Will it hurt?

You are likely to feel some pain from your wound after surgery. We can give painkillers like morphine, into a vein in your arm after the operation. This can be controlled by the patient and is called patient controlled analgesia (PCA).

We can give tablets for pain relief. We will give you a supply of these when you leave hospital. Any pain will normally fade to just a feeling of discomfort within a few days.

You should not take non-steroidal anti-inflammatory drugs (NSAID) after surgery. These type of painkillers can damage your remaining kidney. You will never be able to take these again for life:

- ibuprofen (Nurofen)
- diclofenac (Voltarol)
- naproxen (Naprosyn)

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

We will encourage you to sit out of bed the day after your operation and to walk around the ward. You will be on enhanced recovery after surgery (ERAS). This helps to stop complications with 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 should improve within the first few days at home. You will not need to take any medication for your kidney.

- You should eat a healthy diet and drink plenty of fluids. Do not gain excessive weight as this can put a strain on your kidney.
- The time taken to return to normal activities is different for each person. Do not do any heavy lifting for 12 weeks after surgery. Most donors will need around 4 weeks off work. This depends on what you do for work.

- Do not drive for about 2 to 3 weeks after your operation. Your doctor will tell you when it is safe for you to drive again. This is often 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.

Can I get pregnant?

It is safe for female donors to become pregnant. There is a slight increase in the risk of pre-eclampsia. We strongly advise you to have a planned pregnancy and wait for 1 year after your surgery.

Should you become pregnant, your GP should refer you to a maternity doctor (obstetrician) right away for advice. Or you can let the live donor team know so they can refer you to the renal and obstetrician clinic. You will need regular follow-up. The Obstetric team will arrange this.

The fertility of male donors will not be affected.

How will I be able to afford time off work?

There is a NHS UK scheme that lets donors reclaim necessary expenses like loss of earnings and travel. You must first talk 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 team about any concerns you may have about your finances. Do this 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. You will need a letter from your employer and evidence of your expenses. Or if self-employed account, information and evidence of tax returns.

Psychological effects of kidney donation

It is normal for donors to feel anxious before their surgery. Some donors feel 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 the recipient and donor need to think about the risk of the transplant being unsuccessful. This would 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 if you could cope with the possibility of the transplant failing. There is a UK living kidney donation buddy support service for pre and post donation support. www.donateakidney.co.uk/uk-living-kidney-donation-buddy-support-service-launches/

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 being able 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 often be in a better condition than one from a deceased donor. This is because an approved donor will be fit, healthy and will have excellent kidney function.

The donor and recipient operations follow each other in the same operating theatre at Glenfield Hospital, University Hospitals of Leicester. This means 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?

The NHS Blood and Transplant (NHSBT) published data for Leicester, which is in line with national averages:

- 98 to 99% of kidneys from living donors are functioning 1 year after transplant.
- 95% from deceased donors are functioning 1 year after transplant.
- 92% of kidneys from living donors are functioning 5 years after transplant.
- 86% from deceased donors are functioning 5 years after transplant.

After a transplant, the new kidney will often work well for a long time without dialysis. If the kidney is given from a living donor than it can last for around 15 to 20 years. All of this does depends on many things.

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

We support possible donors for our recipients.

You must have all your first health checks done in the country where you live. You will need to pay for this by yourself. This will include basic tests to confirm your blood group, tissue type, kidney function and virology and possibly genetic screening. If the doctor finds any disease or illness, you will need to get this treated in the country you live in. You will need to give proof of these tests to the Live Donor Co-ordinator team.

If the first screening is satisfactory, we will send you a screening questionnaire to assess your medical suitability. We will give you all information leaflets along with the questionnaire. Once our medical staff get this information and review it in the laboratories, discussed at an MDT and if satisfactory, a letter of support for your visa application will be provided. But the VISA approval is down to the home office not the live donor team.

If we find any disease in the screening process when you are in the UK, not related to the kidney donation surgery, you will need to address this at your own cost in the UK. Or you will need to return to your country of residence for treatment. This may stop you from being a donor.

The NHS will fund all treatment costs related to the live donor nephrectomy operation if 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 choose if you want to give your kidney to someone.

For the person getting the kidney, it means a better chance being healthy for a long time.

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 thinking of being a living kidney donation and would like to talk about this more please contact:

Renal Transplant Live Donor Co-ordinator team

University Hospitals of Leicester

Tel: **0116 258 4117** or **4736** (direct line)

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

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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